I N D E X

SOCIAL SECURITY ADMINISTRATION
POLICY CONFERENCE
Endocrine Disorders in the Disability Programs

Thursday, November 17, 2005

Session Two: Other Endocrine Disorders & Disability
By Dr. Monte Hetland, Facilitator

KEYNOTE: "---" Indicates inaudible in transcript.

Social Security Administration

Policy Conference

Endocrine Disorders in the Disability Programs

(9:20 a.m.)

Overview

by Patricia Jonas,

Social Security Administration, ODISP

MS. JONAS: --- to address concerns about the policies and I think our experience -- when we first began and the challenge was how should both the advocates, the public, the medical professionals interact at those sessions?

And it was kind of funny, the first session that we had I think there was sort of a -- it was almost like a dance. Well, how much do you want me to say? Well, I want you to say this. So, there was sort of a dynamic going on here that was -- seemed a little uncomfortable, and I am hoping that today's session will be much more open for all of you.

One of the reasons for these conferences -- again, it is to look at all of the people who use the disability policy. It is for -- you know, look around at the table -- at any of the tables here where it is a mixture of both SSA people, as well as medical professionals, consumers, advocates. Each of you has a different perspective on these policies that we develop.

And I think one of the purposes of these sessions is to have a discussion about -- not just about the current policy, but where we want to go with these policies. But from your perspective -- and it is fine if you are an SSA person, a DQB, or an OHA, or a DDS, what are the challenges that you are having in using this policy?

This particular listing that we are talking about today, we know it needs changes, and so you can certainly discuss those challenges that you have had with the current policy. Where do you think we should be going with regard to this policy? What things do you think we should be looking at as we develop those changes? So it is open to all of those issues.

One of the things that I think I have seen a challenge for in some of the other programs is when we have had a mixture of people who are unfamiliar with the disability process. Not just -- you know, we are going to be talking about a specific policy today, but how does that policy fit within the whole adjudication process at SSA?

And we are going to have some folks here today to explain -- briefly explain that process. It is a complicated process in many ways and I wouldn't expect if you hadn't had a lot of experience with it, that it would be completely understandable to you.

If during a break you want to talk with someone from SSA who has had experience with that, they can provide a little bit more explanation. But I think it will give you a perspective as to why these rules are important to us.

And you have heard from the people around here from SSA and I think any number of them can help explain that if you have any additional questions about them.

We are making changes to that disability process even as we speak. The Commissioner issued a notice of proposed rule making back in the summer to change the process by which we make decisions on disability claims.

The comment period closed on that in late October and the Commissioner is now looking at the comments. There were almost 900 comments to that NPRM. That is a fairly significant number of comments for something that SSA normally doesn't generate -- in small regulations or small changes in policy, we normally don't get that many.

But I think it reflects a concern from all participants. People who come, you know, into the agency, whether you are a claimant, an advocate, a representative, an adjudicator, people have concerns about that process and want to make it the best one possible.

We won't go into the details of that process change, but if you have questions, please see me and I have got access to some materials for you.

I am going to turn it over to Glenn at this point and let him introduce the next part of this program. Again, I really would encourage all of you, if you are at your table or mixed around with some other tables, to talk with people. This is an important opportunity to get different perspectives on the program.

And feel free -- I know from the consumer's perspective, you know, we are kind of an intimidating bunch. Please -- you know, we normally don't, you know, have horns or anything, so feel free. If your gut issue is that you think you would like to speak about -- outside of the session, please feel free to talk to someone. And Glenn, here is --

Welcome and Introductions

by Glenn Sklar, Associate Commissioner,

Office of Disability, SSA

MR. SKLAR: Good morning. Just a couple of quick words on the logistics for today and how these sessions will work. There will be two main themes for the day. Again, one will be crafting the rules by which people will qualify for endocrine disorders.

What we are talking about, for example, how somebody with type one or type two diabetes might qualify? How somebody with a growth impairment might qualify under what we call our quick screening standard or the listings?

This is one of a couple of ways to get on to Social Security disability or supplement security income. What it is, is a quick screen medically based for very severe impairments.

In other words, if you are completely unable to perform gainful activity, then you would meet this particular criteria, so that is what we are setting up today and looking at.

We have already put out what we call an advance notice of proposed rule making, seeking comments on our existing rules. We know the current rules are somewhat outdated and I am sure you will tell us all about it in areas we need to change and we want you to do that.

Again, this is your opportunity to critique the existing standard as we work towards a new standard and every step of the way you will be involved with this process. When we actually put out what we call proposed rules, we are going to email everybody a copy so you can see what is out there.

And again, you will have another chance to comment before they become final rules. So it is a very participatory process, but a process that is extremely important for us and for our claimants. Again, it is a quick way where people can qualify with very, very severe impairments.

You will also hear another theme today and that is one of work. The idea that Social Security disability is a way to help individuals get back on their feet and hopefully return to work. So our Commissioner has talked a lot about opportunities to integrate the two paths.

In other words, they shouldn't be looked at as two completely different worlds. What we would like to do is talk about ways where individuals with these types of severe impairments can get supports and help from the federal, state and local government to try to get back into the work force and some of the challenges that they face; not an east prospect.

We haven't had great success in that area. Essentially the statistic often cited is that less one percent of individuals who wind up on Social Security disability or SSI disability ultimately wind up going back into the work force. And we would love to see that number rise and we would love to do anything we can to support that endeavor.

In terms of the actual panels today, this morning you will hear a panel which will cover, very thoroughly, type one and type two diabetes. We will also have a parent of an individual with I think type one diabetes, as well as a patient or an individual who has had diabetes actually for 30 years.

So what we do is have the panel run through their presentations. We will then take a short break and then we will have a very interactive session we hope. And again, I realize this is a fairly small room, which is not so good on the one hand; on the other hand, hopefully, we will be in close contact and everybody will feel the need to contribute and be interactive.

Again, that helps us so much. This is all about hearing from all of you and hearing your comments, both from folks outside of SSA, from adjudicators within SSA on how the rules actually work, but it only works if everybody is very interactive and very participatory.

So with that, I think we are about ready to turn it over to our panel. I am gong to introduce Dr. Hetland, who is going to introduce our panelists. And actually Cathy Lively, who -- do you think it would be helpful to take two or three minutes to run through the process for awarding benefits?

MS. LIVELY: I think so.

MR. SKLAR: Okay, great. Because we found when we don’t do this, that we often wind up backing up and trying to explain it later on, so two or three minutes. That is a great challenge for you, Cathy.

MS. LIVELY: Absolutely. Before I start that, I do want to take care of a couple of housekeeping chores. First, the fire exits, when you go through this door, immediately to your left, behind the sheer curtains is the fire exit. So it is very close, just to let you know that.

The restrooms, through these doors, straight ahead, you go to the fitness center and the restrooms are immediately to the right. Cell phones, if you would please, put those on mute. Lunch will be served at 12:15 to 1:15.

When we get to the participatory part of the presentation, if you will, please, identify yourself before you speak. The meeting is being transcribe and so we need that information for the record.

And if you would like a copy of the transcript of today's session, let the people know at the registration desk and they will be able to get this to you.

Overview of the Disability Process - How We Use Listings

by Cathy Lively, Team Leader, Medical Criteria Team

Office of Medical Disability, SSA

MS. LIVELY: Okay, Glenn is giving me a pictural and so I am going to talk fast. And because I have explained the process in a few minutes, it can be very confusing. So what we will do to help you as a roadmap for this explanation, and also to flesh out the details that I will be leaving out, if you will pull out your folder and on the right-hand side, behind the huge package of stapled material, there is a four-page -- I think it is a four-page document that basically we can use as a really quick guideline for what I am going to be talking about.

There is no title on this. It simply starts with "here is a brief explanation of our disability programs." Now, the first section talks about the two programs that provide benefits, SSDI and SSI. The --- section gives you some information on the relationship of Medicare and Medicaid to these two programs.

I am going to start with our definition of disability. If you look at the bottom of that first page and look at this with me, in both of the programs disability must be the result of a medically determinable physical or mental impairment or a combination of impairments that is expected to result in --- that has lasted or can be expected to last for a continuous period of at least 12 months.

Now for adults, this impairment must result in the inability to do any substantial, gainful activity. And for children marked and severe functional limitations. Now, that is quite a mouthful. The best way to explain it is to talk about how we operationalize it? How do we actually decide that a person is disabled based on this definition?

If you flip to the next page, four adults will follow a five-step process. At the first step, we determine -- or we ask the question are you working? And if you are working, are you earning at a substantial, gainful level? If you --- that is part of the definition.

--- rules, it is a specified amount. It is not a static amount, it is set by the Commissioner, it is currently $680 a month. So if you are not working or if you are working, but your earnings are not beyond this level, then we move onto the next step.

And at the second step, we want to know whether you have a severe impairment. And as you might guess, that has a specific rule in our program. A severe impairment is nothing more than a slight abnormality or combination of abnormalities that causes more than the normal impact on basic work activities.

So these are things like walking, standing, lifting, carrying. So if you have this slight -- this impairment that results in this normal impact, you meet the second step requirement and you move onto the third step.

And that is, does your impairment meet or equal a listing? Well, as Glenn pointed out, this is the step that we are going to focus on today. But what does it mean? Well, the listing is essence are pretty self-explanatory.

It is a list of very severe impairments, life threatening impairments, that we use as screening criteria. We never deny disability based on these listings. We use them for identifying medical findings that are so severe that if your impairment meets these requirements, then we deem you disabled and we don't look at any other factors.

We don't consider vocational factors, your age, your education, your work experience. We simply say because your impairment is this bad it meets these medical criteria, then in essence you are disabled.

The listings are in this big fat blue book that is on your table. And of course, the endocrine listings are what we will be using in today's session.

Now, suppose you have an impairment that is not on this list? Well, your impairment can still equal the listings. There are three different ways. If for example, your impairment is on the list, but you don't have the exact --- or it is not on the list, but it is equally severe, or you have a combination of less severe impairments. In those three ways the impairment can equal the listings.

Many people think that well, if your impairment doesn't meet or equal the listings, then that is the end of the process, SSA is not going to find you disabled. But that is not the case, we have two additional steps in the adult process.

Up to this point, we have been looking at your impairment and asking does it meet these severity criteria? But now, in the process we reverse our thinking. We recognize that you have a severe impairment, that it causes limitations and we want to learn what you can do despite those limitations. We call this your residual functional capacity.

How much can you still do? How far can you walk? Can you sit? Can you stand? And this is the residual functional capacity assessment. And we take this assessment and at step four, we ask the question if you have had past work, can you still do that past work based on this residual functional capacity assessment?

If you can’t, we move onto the final step of the process and that is can you do any work in the national economy as it is typically performed in any other work? And to do this, we look at your remaining capacity. We look at your age, your education and we make a vocational assessment.

And if you can’t do other work based on all these factors, this assessment, and the vocational assessment, then we determine you are not disabled.

So those are the five steps basically of the adult process. And as I say, the handout will kind of flesh in all the details that I am not able to give you in this very brief summary.

Now, for children, we will follow a three-step process. As I said before, the standard is that the impairment must result in marked and severe functional limitations.

The first two steps of the process are exactly the same as for adults. Is the child working? Does the impairment -- is it a severe impairment? At third step, we also use listings to determine whether the impairment meets or equals a listing, but we also have a step that is called functionally equaling listings.

And in this case, we look at the child’s impairment of functional limitations and we evaluate those in the current text of six domains. These are acquire and using information, attending and completing tasks, interacting and relating with others, moving about and --- objects, caring for yourself and health and physical well-being.

And we compare the impairment to these broad areas of functioning and if the child’s impairment is -- results in marked limitations in two of these areas or an extreme limitation in one, we determine the child disabled.

So, that is it in a nutshell. Please refer to the handout -- the four pages. I think that will kind of make the picture much clearer for you. And with that Dr. Hetland?

Session One: Adult and Pediatric Diabetes and Disability

by Dr. Monte Hetland, Moderator

DR. HETLAND: Good morning. I am Dr. Monte Hetland. I am the Pediatric Medical Officer in the Central Office in Baltimore.

And it is my pleasure to introduce our speakers this morning. Prior to that, I would like to point out in the blue book where are the specific listings that we are going to be talking about today.

The adult endocrine listings are on page 96, give or take one or two before. And the pediatric endocrine listings are on pages 221 and 222. I think we have surmounted our technical difficulties.

I can also let you know that one of our speakers, who had a miscommunication, but he is on his way, that is Dr. Reed. And because of that I am going to change our order of speakers just slightly.

Our first speaker will be Dr. Dorothy Becker, who is a Professor of Pediatrics at the University of Pittsburgh School of Medicine. She is also Director of the Diabetes Program at Children's Hospital of Pittsburgh.

Our next speaker will be Dorothy Jordon, followed by Maureen McGrath, who will be sharing their personal experiences. And then, Dr. Reed, who is enroute, we will give him a chance to catch his breath when he gets here and we will have him be the fourth speaker. Dr. Becker?

Diabetes in Childhood

by Dorothy Becker, M.D.

Professor of Pediatrics,

University of Pittsburgh School of Medicine

DR. BECKER: Well, thank you very much. And I appreciate you taking care of my disability, which is not one, which is being short and so I do have a podium I can see over.

But I am going to talk about something else and as I was listening to the introduction, I was sort of a little shocked because we have 2,000 people -- kids with diabetes that we follow in our center and the last definition of disability in childhood would make every single one of my kids disabled and I don't think any of us want that.

Actually, I probably need to confess that I always felt the opposite and I have not wanted any of my children with diabetes to be deemed disabled because my job is to keep them functioning as closely as normally as possible. So my first reaction to defining that any of my children is a not.

And the advice of one of my close friends, who will be here tomorrow, is get over it because it will need an act of congress to make a change and as I had said the other day, I have no problem with changing acts of congress if that is what we need to do.

So I think that what I would like to do is point out what happens to children with diabetes. In my 30 years, I have learned how difficult a disorder it is and see what we can do to help to make these people productive members of society, not to get them back to work, but to be able to make them work forever until they are 67 or 68 or whatever congress decides the retiring age is by the time they grow up. And be productive, normal individuals and make them healthy grandparents. And we now know we can do that. We just need the tools with which to do it and one of those tools is money.

(Slide)

So I am just going to start by talking about definitions because one of the questions I had was what about type two diabetes? And we have to be aware that there are a lot of different kinds of diabetes in childhood and I hit the press recently by saying that we should get -- probably there is little type two diabetes in children, especially young children.

I think it is what we have at the bottom there. Let's see if my pointer works. I don't see it. Oh, there it is. I think that most young children who are diagnosed as type two diabetes have, what I call, double diabetes and what some other people call type one-and-a-half diabetes. So we will get to that just now, but there are other insulin deficient forms of diabetes and they also have their impairments. It does not have to be type one diabetes.

And the clinical type two diabetes is treated with insulin and therefore needs to be dealt with the same way as any other insulin treated diabetes.

(Slide)

So type one diabetes is the commonest chronic disease in childhood, second to asthma. Most people don't recognize that. And the difference is, it is -- asthma is more intermittently and diabetes is there all the time. It is the most common --- associated disease in childhood.

(Slide)

And type one diabetes is part of the patient's life whether it be a child or an adult, all day, every day and at the moment, forever, because we don't have a cure and it is not going to go away.

And I am sure you will hear from the people who have diabetes or the parents is that they have to think about it constantly. Well, if that falls within the definition of disabled, you can see why I said that would be every single one of our patients, but you probably will be able to look around this room and not tell which person has diabetes and which one does not.

(Slide)

So what are we trying to prevent? We are trying to prevent the complications. And the complications that are the ones of concern in childhood are number one, number two, number three and number four and number five hypoglycemia, so I didn't number them, but that is the biggest thing. And the major fear of the parents of a child with diabetes is death from hypoglycemia.

Now that is very rare. It is a very rare phenomenon. Most of us in our experience, only a few in our clinical lifetimes -- even though we have big clinics, it is certainly a concern that is greater than somebody who does not have diabetes. And we have to be aware of it and we have to do everything we possibly can to prevent it.

And as tools are being developed, like more sophisticated glucose monitoring tools, it will become more expensive than it is now.

Seizures do happen. They happen all the time. They are very frightening. And when I say happen all the time, they happen all the time to us because we have 2,000 patients. And most patients never experience a seizure, but it can occur at any time and it is more likely to occur in childhood diabetes than an adult. And it will probably be like somebody with a seizure disorder.

And we would say it is preventable and we always say yes, the patient did this or did that or should have done this or should have done that. Well, it is true in hindsight, but it is not always easy to predict who is going to have a seizure and the younger the child, the greater the risk of severe hypoglycemia, the greater the risk of seizures.

What is interesting is I have just written a chapter and again reviewed the literature on the chronic effects of severe hypoglycemia in people with diabetes. And there is no evidence that one or even five or six seizures causes any long-term impairment, except in the young child under the age of five. But older people with diabetes, hypoglycemia is not being shown to have long-term consequences. But the child under five, there is a significant cognizant effect and I will come to that in a minute.

The listing that is in the book is recurrent ketoacidosis and I am going to talk about that just now. And when we discussed the listings with my pediatric colleagues, it was amazing how we all totally agreed and we don't often, but in this we totally agreed that the recurrent keoacidosis should not be the prime disability. It is usually either an economic problem or a psychosocial problem. It is not a problem with diabetes and throwing money at it doesn't always solve it.

In fact, sometimes recurrent ketoacidosis, being very cynical, may be a way of getting money and that is certainly a way of getting attention. I will come to that.

Growth failure is a consequence of under insulinization. It is not the growth failure that is a disability; it is the poor diabetes control and the consequences of that that will cause all of the things at the bottom, chronic complications, blindness, kidney.

So growth failure is a sign that something is very wrong. And in the United States, I don't think we see much growth failure due to diabetes anymore. I have just been sent a manuscript from China, so yes, it still happens, but I haven't see it for years and years, although we wrote some papers a long time ago. So it shouldn't happen in big clinics, but it might happen in people who don't have access to diabetes care.

(Slide)

So what I think we need to do is think not what do we do about people who are really disabled. What we need to do is prevent the hypoglycemia. Prevent the chronic complications. And what I would like to do today is say how can we support these families to prevent the things that can happen to them. And certainly in the children under the age of six, the preschool child, needs adult care with them all the time.

(Slide)

So those are the two things that I want to concentrate today. It is what happens in childhood. It is the hypoglycemia, as I have described, and the chronic complications which we are trying to prevent, which I must tell you I used to see when I was young. I cannot teach my trainees chronic complications in children any more because we don’t see it any more.

But it happens in adulthood and the beginnings of it start in childhood, so we have to get superb control in childhood to prevent chronic complications in adulthood.

And the first one that I want to talk about -- and to just get back for a second is the impaired cognitive function in children who are diagnosed under the age of six.

(Slide)

This is our data from Pittsburgh, but there is data from around the world but it looks the same. And this is looking at children when they are teenagers who were diagnosed under the age of six. And that is the first bar that says EOD compared to the second bar which is children who were diagnosed over the age of six, which --- diabetes LOD compared to their non-diabetic siblings, non-diabetic controls.

And if you just look on -- this is an IQ test. It is a cognitive function test that I do, together with my colleague, Dr. Chris Ryan, and you can see the EOD score much lower than the other two groups on -- this happens to be a vocabulary score. This happens on a number of scores, memory, and all sorts of things are coming up right now. And even IQ scores are a couple of points lower. So you would say okay, if it is clinically significant is this disabling?

(Slide)

Well, this slide shows the proportion of subjects missing criteria that neuropsychologists use for clinically significant contaminants. And if you look at the red bar, that is the early onset, 24 percent of our population -- now these were people diagnosed a long time ago and I hope we are better at it now because we have new tools -- 24 percent meet clinically significant impairment compared to the later onset and the controls.

What appears to me that these young children have the risk of becoming disabled and they need all our attention, everything we can possibly give them. And you can say okay, would the school teacher notice? This is not worse than the average American, we have many kids who have this degree of clinical impairment. But this is something that is preventable.

And okay, say they wouldn't have been -- they wouldn't have been an Einstein and maybe without diabetes they become not quite an Einstein. They can still be very, very, very functional people and everything depends on the genes they are given when they are born.

If they are given lots of genes for a very high IQ, you are not going to know the difference. But if they are given the genes for borderline IQ and you give them diabetes on top of it, you will notice the difference.

(Slide)

So early onset of diabetes does give some degree of cognizant impairment and in the --- analysis there is significant differences, but not every child is affected, so just because a child is under the age of five, it doesn't mean that child is going to be cognitively impaired. We just don't know which ones are going to be, but what we do know, without really good data, there are associations -- and associations aren't proof, but there are associations with a frequency of hypoglycemia. And children under the age of six have more frequent hypoglycemia than older children. The better you control the blood sugars, the greater the risk for hypoglycemia.

But there is also data now that very high blood sugars can impair cognitive function. So as a therapist, we are betwixt and between and the very British saying is between the devil and the deep blue sea. And I think in America you say between a rock and a hard place. Whichever one you want to call it, you have got to prevent hypoglycemia, but you also have got to prevent the high blood sugars.

(Slide)

But it is not only the children under age of five and this is the word from my colleague, Chris Ryan. He looks at adults -- these are our kids who are now grown up. And looked at those who grew up -- they are now age 26, 27, those with and without neuropathy. And these scores just mean average scores and zero would be normal on this slide. I am sorry -- oh, here it is.

So anybody who is here would be normal -- and I hope that is most of us, with some wobble around this line. So the red is -- well, the normal population would be people with diabetes, without neuropathy, have psychomotor scores that are normal. And people in the white are people with diabetes who have neuropathy.

And so these are grown up people who have not only neuropathy of their limbs, but there is probably some degree of neuropathy of the brain, so they don’t think as well as people without neuropathy. And this is not childhood, but again, this is a childhood population.

(Slide)

All right, let’s move to recurrent ketoacidosis. Recurrent ketoacidosis is a medical failure. It is a failure of the doctors, the team, the family. It is always, always, always, always due to insufficient insulin. It is either omission of insulin or it is due to somebody not monitoring that child well enough to recognize that they need to increase the insulin doses.

And why is this? Is it economic instability? Is it because it is a parent at work and there is nobody at home to look after the child? Is it nobody to supervise that child? Is it because they can never get to a doctor? Is it because they can't afford insulin, which is true in some countries and horrifyingly sometimes in our own country?

Or is it always psychosocial because of a disruptive family? And probably those two things go together. I think the psychosocial part of it probably is the more common in my experience and I think most of my pediatric colleagues would agree.

As I said before, growth failure is due to inadequate medical care. Is growth failure a sign that that child needs help to get to the medical team more often, more frequently? Or is it psychosocial issues? Again, each case has to be taken as an individual. But I was just trying to do some quick arithmetic and the cost of diabetes -- and I think it turned out to be about an income of 8,600 -- I was kind of multiplying it monthly and level out.

If you think, that if a patient test their blood sugar four times a day, those strips are $.70 each, so that is $4 a day, if they test four to six times a day, which young children need to do. That is irrespective of going to the doctor, paying $12 or $16 for parking and -- even if the insurance pays for the visits and the lab tests.

So I can see diabetes taking half of that income before they have even eaten anything and then there is not enough money for food. So I think growth failure --- that there is some major economic stress and maybe it is a sign of whether they need disability, but that family needs help.

(Slide)

Well, what are your definitions? How many episodes of recurrent ketoacidosis? And some of these may be treated at home; it is not necessarily hospitalization. I spend my weekends on the telephone treating vomiting, diarrhea, high blood sugars, ketones, over the phone. Nobody pays me to do it. They never see the inside of a hospital.

The thing with recurrent ketoacidosis -- so how many? I don't know. We all threw this around and we came up with more than two, which is three or more a year.

How many hospitalizations? For sure, you could say somebody on a pump has two accidents, maybe three a year. But what we had to work out is it due to financial constraints or is it something else? And I don't know how to do that.

As I said, type two diabetes in childhood is rare before adolescence. And if a child is ketotic I think they should be treated as type one diabetes irrespective of what the Commission calls them. But in a young child, we need food and exercise control and if the patient's parent is at work and are left with a 12-year-old sib, that is not going to happen.

(Slide)

So I would like the definition of disability to pediatric type one diabetes to be a child who has the disorder who is under the age of six, where the presence of a parent or another adult is mandatory and it is a significant limitation control to other children.

And it is interesting that I was talking to one of my colleagues in Finland over the weekend, who happens to have diabetes himself. He said well, of course -- and in Finland -- we think we were being smart, but in Finland they automatically double the government support to a family if a child has diabetes under the age of six.

So every family has “X” number of dollars if they have a child, “X” number of more dollars if they have a child with diabetes, and “X” number of more dollars if that child is under the age of six. So we are not inventing the world here, it has already been invented.

(Slide)

And I just want to point out again what I said earlier, this is making late onset children in yellow compared to normal diabetic controls and cognitive function more normal, so that is why we are concentrating on the younger children.

(Slide)

Recurrent ketoacidosis should be considered a disability that qualify for SSI, if financial support is deemed a potential solution for its prevention and I guess

--- how do we implement this.

(Slide)

I would like all my patients to be like this guy that is in the front, who I have looked after since he was little. He was a Pittsburgh --- player; he is now on the NFL. He has normal A1C hemoglobins. He has never been unconscious. And he is going to become an attorney, I think. And I am trying to get him out of NFL because it is not my favorite cup of tea and he promised to do so soon. So we can make people productive in every way.

(Slide)

This is not a child, it is an adult. It is --- abdomen showing an insulin pump and the lines and a little sensor on the left. And we are doing this more, and more, and more and it cost a lot of money and we don't need pumps. My patient didn't get a pump because he thought it would last about three seconds on the football field, so he gets injections. So you don't need a pump to get perfect control.

(Slide)

But we are giving pumps to children. ---, who is the son of one of my patients.

(Slide)

So I was asked to address these questions and so I am starting with type two diabetes in childhood. It is complex and not seen in an age group we consider for -- I think that if a child with diabetes -- it doesn't matter what you call them, if they need the criteria we should consider them disabled.

Young children are the most important group to consider and an age criterion with the financial constraints, which I think are too low from what I heard this morning. And insulin pump therapy, should that be considered differently? It is complex. It is not for all patients. It is more expensive.

You can treat people without a pump, but I must say if I had diabetes, I would preferably use a pump. But, even though the pump companies tell you that control is better on a pump, nobody has proven that yet. And so it doesn't have to be, but I would hate financial constraints to be a reason for one of my patients not to be able to have a pump if I think, and they think that this is the right treatment for them. And I really think that would be health care rationing.

And I just want to make a plea that diabetes is very expensive and the impact of the costs can influence the outcome. Thank you.

(Applause)

DR. HETLAND: We can go back to our original schedule. Dr. Reed is here and will be talking about adult diabetes. Pardon me for not introducing him. He is a Professor of Medicine at the Morehouse School of Medicine and is Director of Pediatrics -- no, Director of Diabetes, correct?

Presentation

by James Reed, M.D.

Chief, Endocrinology

Director, Clinical Research Center

Morehouse School of Medicine

Morehouse College

DR. REED: Please let me apologize for being late. I had the time down wrong and I just got back from Dallas, Texas. And I --- I am losing my voice because it was freezing there.

But one of the things that I would start out by saying that diabetes is really -- has become an epidemic. And so this is going to become one of the most important problems I think that Social Security Disability is going to be dealing with.

And I would like to add something to what the previous speaker said about children. Type two diabetes is not just epidemic among adults right now. Type two diabetes is epidemic among children. Some of my most frequent calls now from some of my pediatric friends, who want -- because there are no drugs on the market that are approved for treating diabetes in children, are calling about some of the medications that we are using in adults.

And I think that that is a very important concept to be considered as you think about rewriting what disability is, because the disability for type two diabetes is going to be occurring a lot earlier and you are going to get a lot more of it.

And of course, this is being driven by another epidemic in the country, which is the epidemic of obesity. And I don’t know whether or not you are considering making obesity a disability point or not, but type two diabetes in adults and children is clearly be driven by obesity.

We now know that 18 percent of the children -- the adolescent population in the country are obese. And there are now several very excellent papers that have been written concerning type two diabetes in children out of Texas and the Hispanic and the Mexican-American population our of Arkansas or

African-American population. And one out of Johns Hopkins I think that is a predominantly Caucasian population, so it is not race specific. You know, fat people are developing all over the country and until we change our lifestyles we are not going to be able to stop that.

And I would also like to preface my remarks by saying that number one, I don't think the diagnosis of diabetes is a disabling diabetes. I spent part of my early life in the Army, fighting the Army over discharging everybody the minute they came down with a diagnosis of diabetes.

And I might add that I think I won some of those battles because it is now not an automatic discharge for some person from the U. S. Army just because they are diagnosed with diabetes. There may be some limitations on what they are allowed to do, but with the type two diabetes they are allowed to do anything that anybody else. And with type one diabetes, some of them still remain in the Army.

So I don't think just by being diagnosed with diabetes that you are automatically disabled and I would not like to leave here having you think that that is the position I think.

I think as long as we control diabetes better with the prevention that was the last slide that was just showing, I think both children and adults would all benefit to a great deal and it would make your life at Social Security a lot easier because there would be far less disability for you to have to consider.

I consider the disability for diabetes to be a part -- to be only for a complication. It is the complications of diabetes that lead to the disabilities. And not all complications for diabetes make patients totally disabled because if that were true, you would have something like about 20 to 22 million disabled people to consider around the country now since that is the estimated number of diabetics in this country at the present time.

So I think that we should consider disability for diabetes both for type one and type two and I do not make a distinction between the disability for type one diabetes or type two diabetes because if all type two diabetics live long enough, they will all become insulin requiring or insulin dependent, which is the old way that we defined diabetes, even though we now define it by type one and type two diabetes.

So there are children with type two diabetes, of course, but the bulk of -- and the bulk of diabetes in this country, about 95 percent of it, is all type two diabetes. And when you start adding the children that is probably going to go a lot higher.

So what are the disabling features of diabetes? What complications are going to make a patient disabled? Let me take the one that I think is probably the most serious and one of the most feared, is blindness.

We know that type two diabetes not controlled well will develop blindness. The term that you are using, which I think -- which is one of the terms that I am going to recommend that you change, but it is by proliferative (sic) -- it is proliferative retinopathy that patients get that leads to blindness.

And of course -- and I think that this should be considered under the same criteria by which we consider blindness, regardless of cause. But what we need to know is that the leading cause of blindness in this country that you will be considering is the blindness that is secondary to diabetes. And I don’t think I need to impress upon you how disabling blindness can be if you have had a normal functioning life.

So consider blindness and your Social Security disability outlines the same way that you would consider blindness as any other cause that you think a person should go blind. But I would change the terminology that you use in the disability code and really make that because it is a specific type of disease that causes diabetics to go blind.

And the second huge disability from diabetes in this country is renal failure. Diabetes is the leading cause of renal failure in the country. Oh, I am sorry. I will try and speak a little bit louder, but I am a bit hoarse. Okay.

I think that renal failure is really -- and this is probably the greatest cost -- and not just the Social Security system, this is the greatest cost of the health care system in the country is renal failure.

And of course -- and the leading cause of renal failure in this country is diabetes. Percentage wise it is greater among the type one diabetics, but because type two diabetics outnumber type one diabetics by an astronomical figure, something like about ten times more common, the greatest number of type two diabetics that have gone into renal failure.

And the cost of treating a patient with renal failure -- and if the patient does not get a transplant, which is the best way for dealing with renal failure in the country. But if the patient has to be dialyzed, and he is going to be dialyzed two to three times a week, which is at least three to five hours at a time. Then, this clearly renders that patient, regardless of what his occupation was, disabled.

And I think that you have to clearly write guidelines that are going to clearly determine what do you do Social Security wise for people who have renal failure and require dialysis? And with diabetes being the most common cause of this abnormality, I think that that is something that is going to clearly have to be looked at a lot more seriously and dealt with a lot more seriously when you reconstruct these guidelines to deal disability from diabetes.

Although it is not only costly to the Social Security system, it is one of the most costly diseases for the health care system. It costs approximately $65,000 a year just to dialyze a patient, not adding all the other complications, the frequent hospitalizations and all the other things that goes with it.

And since we don’t have enough kidneys to go around to transplant everybody, I think that this is something that you are clearly going to have to deal with.

Another huge, I think, factor that you are going to have to deal with Social Security Disability is how do you deal with neuropathy? And I think that is probably -- as I read your guidelines, I think that is the most inadequate portion of the guidelines. You have no clear cut definitions of neuropathy.

And I think that we have to clearly establish good definitions and good guidelines for neuropathy, but realizing that there is more than one type of neuropathy that diabetics develop.

Peripheral neuropathy is the one that most adults see, but I think probably -- I would probably go to my pediatric colleague for this, but I think in children it is probably the sympathetic neuropathy. But both of those can have great --- of disability.

It is the peripheral neuropathy --- in adults that really causes the greatest amount of disability. And you don't have to have had an amputation. And I think that is one thing that two of the most -- the definitions seem to be defined by whether or not you have amputated a limb.

But you don't have to have an amputation to be disabled from a peripheral neuropathy. And I think that you need to really take that in great consideration when you look at whether or not you are going to evaluate somebody for a disability for a peripheral neuropathy, because if you can only walk a half a block -- if you have a manual laboring job, you are disabled.

As a physician, that probably would not make that much difference to most of us unless we had to stand up in the operating room for a long time. And then as a physician it would mean -- it would add to your disability problem.

So I think what we have -- what you have to do when you do rewrite these guidelines, you have to sort to tailor them not to all. You cannot write a global definition for any of these.

You have to tailor them to the lifestyle or to what the person does to make a --- on his --- occupation because I think if we try to retrain everybody -- that seems to be the idea that a lot of people have, if you become disabled for one thing, you can be retrained for another. I think if we go down that path, I think that you are -- I think that we are fighting a losing battle and that does seem to be the trend in a lot of the things that we do.

Evaluating sympathetic neuropathy is quite difficult. It is probably one of the more difficult things to equate disability to. But if you have gastroparesis, which is the one thing that I think that is -- it is the one thing that everybody looks at for sympathetic neuropathy.

But there are other forms of sympathetic neuropathy that I think we clearly need to look at, other than gastroparesis. I do not think that this disables all people, but there are some people, depending upon what their job categories are, that this would make them have an inability to perform the same task and they may not be able to make a living based upon what their previous occupations were.

Another form of an intestinal problem that we are now finding very much so in adult diabetics is abdominal angina. We think of angina as meaning only a heart disease, but there are many type two diabetic patients now who I am beginning to see who has abdominal angina.

And it is caused by exactly the same thing that causes them to have angina of the heart. When there is no place I could find -- and maybe I didn’t read it as carefully as I should, but there is no place that I could find in the guidelines where you actually talked about this as a disabling problem.

If you can say that a person can be disabled from cardiac angina, clearly a person can be disabled from abdominal angina and I won’t go -- I don’t have the time and I don’t think that this is the place for me to discuss with you what abdominal angina is, but it is a real condition caused by exactly the same thing that causes people to cardiac angina, except that it is affecting the vessels of the gut.

You have to consume oxygen to digest food and when you do this, if you can't get enough air, you know, you get angina and that is what causes you to have cardiac angina and that is what causes you to have abdominal angina. And so I think that you really have to think closely about this.

One of the things that I keep getting telephone calls now about from people who employ diabetics, and this is especially true for truck drivers and I also have a couple of pilots, that have type two diabetes and clearly, this is threatening for their occupations.

I recently found out from one of my own patients who had type two diabetes, who was a truck driver and I had to -- because his diabetes was not controlled, we had to go to the insulin. And for his job as a truck driver, he automatically got fired.

Needless to say, I feel very guilty about that, but I do think that it was the medication that he needed. So these are the kinds of things, that I don't think we hear enough about. When we are trying to evaluate people with this condition that we don't take the individual into consideration. You cannot make global definitions to combat any of this.

So we have to make these definitions a lot more individualized based upon the person's occupation because after all I think disability is based upon somebody's ability to earn a living or to work. So you have to tailor the definition based upon what the occupation is as to whether or not you are going to declare a person disabled from this particular complication.

Neuropathy -- and I think that neuropathy is something else that you are going to have to look closely at in the definitions when you start rewriting the guidelines for this because there are all kinds of neuropathy.

Of course, one of the most common neuropathies is diabetic neuropathy, but I don’t think it is the most common. I think alcoholic neuropathy in this country is probably more common than anything else because we have a country of boozers, but nonetheless, neuropathy can be disabling.

And I think we have to think -- when you think about neuropathy, it is not disabling for somebody who sits at a desk all day, but neuropathy is disabling for somebody who climbs ladders, or somebody who is a construction worker, or for somebody who has to run around as a waiter at a restaurant, a neuropathy then, especially --- neuropathy becomes disabling for that particular individual.

So again, you have to look at neuropathy based upon the occupation that the person has when you start evaluating the person as to whether or not they are disabled.

So what is going on now -- yes, and I agree that most of this is preventable, but I don’t think -- as I read what I was asked to do here, I don’t think that Social Security Disability is going to deal our sick health care system, which is really what is needed to be revised because I agree that I think 75 to 80 percent of all of this could be prevented if diabetes in both type one and type two diabetes was controlled better. And I think the health care system has to come up with a way to control it better.

But since I don’t see that on the horizon, I don’t see the health care system in this country changing significantly over the next -- not at least during my lifetime.

I think that we have to figure out a way -- when the health care system has failed because I consider when a person with diabetes get to be disabled from this diabetes it is because we in the health care system has failed. There has been a failure along the line to allow these complications to occur because we know that they are preventable.

So what I would plead with you when you start this process of revising these that we, number one, take each complication and individualize it to the occupation of the person that you are trying -- that you are going to evaluate. It will make your guideline look a lot thicker, I admit.

And I apologize for giving you more work and giving you more verbage to put out, but I think if you are going to be fair and honest about it, I think that that is going to be necessary. You can no longer make a global definition for any disability that is going to cover the entire population.
You have to base it upon the particular occupation of the individual.

And I am going to stop here because I -- my whole aim was to answer questions about this because I think that there should be a lot of questions about this. The people who have read these guidelines, I think that there should be a lot of questions about how we deal with them.

And I also think that the question should be asked is who is to deal with the prevention, which I think is clearly the most important part? And I do think that the Social Security Department probably has some -- especially now as it comes up with children.

But I would raise the definition above the age of 60, especially since I know that type two diabetes is now becoming epidemic in children and all that means is that you are going to be seeing complications 10 and 15 years early for the heart attacks and the strokes that you are getting from the diabetics that have been uncontrolled.

The uncontrolled children now that are coming along -- and the youngest child that I have seen who clearly has type two diabetes by every definition that you could get at seven years old, but he is also three times his normal body weight. So that until we can get rid of the McDonald’s and the Kentucky Fried Chicken and do something else about our school system, this is going to be a coming epidemic as far as disability is concerned and it is going to become a lot earlier.

We are going to see the heart attacks and the strokes in the 25 and the 30-year old that is going to be secondary to their poorly controlled diabetes. Thank you.

(Applause)

Presentation

by Dorothy Jordon, Parent Participant

MS. JORDON: Hello. Thank you. I would like to thank Maureen for inviting me to come and talk about my daughter, Kathleen, which is kind of one of my favorite subjects, although I don't get this opportunity to speak to so many people at the same time.

To give you a little bit of background about myself. I am a clinical nurse specialist. I am a registered nurse with an advanced degree in nursing and a master's in child health nursing.

In October of 1997, when I reflect on it, you know, I realize now of course, hindsight, I had been taking Kathleen to our pediatrician for probably over a year, probably a year-and-a-half with vague things, headaches, stomach aches, vaginal yeast infections, which, you know, is unusual for a girl that age.

Every time we went to the dentist the -- my pediatric dentist would say, you know, she really needs to work on those gums and would say okay, you know. And Kathleen had a great diet, you know, typical -- like kid things to eat, you know, had a sweet tooth, but with my background I was pretty focused on proper nutrition and so these things would come and go.

But for check ups, you know, she was healthy and no problems. And then over a weekend in October of '97, I took a look at her and I thought, you know what? I think that she is thinner and so I was kind of keeping an eye on her. And on the way home from a soccer game we stopped five times for her to go to the bathroom to urinate.

And I am probably --- it is probably more, maybe over four or five days. And so I am thinking about this and in the back of my mind -- you know, being a nurse, I am thinking I don't want to go down this path because I think I know we are heading and I just kept on.

I didn't say anything to my husband, who is the biggest worry wort. I thought oh, he won't sleep or he will run us to the ER because she wasn't having any significant issues. And so I thought okay, I have to put her on the scale and she had lost a significant amount of weight.

And so I went down to the local drugstore and got strips to dip her urine and meanwhile Kathleen is dressed -- it is a Sunday afternoon. Now we are at Sunday, you know, this is -- I said it started four or five days earlier, and there she is dressed in her cowgirl outfit to go to a friend's birthday party.

And so I had her urinate on the strip and low and behold, you know, tons of glucose in her urine. And so I said to my husband, I think Kathleen is not going to the party and I think that Kathleen is diabetes. And he said what? And I said I think Kathleen has diabetes.

And so I called a friend who is a pediatrician and I had done some work at -- well, it was just called Egleston then, but Children's Health Care of Atlanta at Egleston. And I said Kathleen has diabetes. Who is the endocrinologist on call because I think we need to -- you know, it is time to go?

And so we went to the ER and Kathleen was diagnosed and in fact was diagnosed by Dr. Parks who is sitting at the table right here. We were sent home that night. Kathleen wasn't indeed ill. She wasn't in ketoacidosis. She had a very high glucose reading, probably 500-something. I can't quite remember.

And so I went home with insulin that night and, of course, would return to the clinic for, you know, over the next few days for education, diabetes education. And the crazy thing is, in all of my nursing, diabetes was the one disease that I totally avoided because I said my focus was, you know, I ended up focusing on children with terminalis and chronic - specifically cystic fibrosis and children with cancer and then focusing on adolescence in particular with, you know, issues of those.

So I thought, you know, here -- I put Kathleen to bed and we went and, you know, I just -- you know, my whole attitude I agree is this is -- you know, we are not going to -- we are going to do everything we can to be normal because she can be normal.

So I put her to bed and went out in my backyard and just sobbed. I thought I cannot believe this. And so it was coming back to get me after saying, you know, I don't want to take of kids with diabetes. I never said that out loud, but in my mind.

So I go back that morning to Kathleen -- or that afternoon, and, you know, the fact that she was going to the hospital. I mean, she didn't -- she was like okay, whatever we are going to do and, you know, mom looks okay. I am looking at mom and she is okay, so I will go along with this and I will be okay.

But her biggest devastation was she could not go to the birthday party in her cowgirl outfit, so that is the perspective of a nine-year-old. Excuse me. So the next day we go to school and so what does that mean? Well, --- school. They had never had a child with diabetes.

So for a parent it means establishing -- educating and establishing standard for them to take care of her. To make there is, you know, gummies in case she has low blood sugar, all over the school.

You know, fortunately, I am in a position that I didn't have to be at a particular office or clinic or hospital, you know, 7:00 a.m, you know, until 5:00 or

6:00 at night. My schedule is flexible and I was able to go and do this. And do whatever it, you know, meant to take care of her, to make her feel normal and, you know, but yet, you know, come back here and surround her with the circles of, you know, people being educated, the proper medication, just whatever it took to support her.

And this kid didn't miss a beat. I mean, she is -- okay, activities. So then what do you do about activities? You educate. Again, you educate everyone who will be around her. No matter what it is, even if it is just for an hour.

Does she spend the night? Yes, but you have to send her with glucagon in case she becomes unconscious. You have to, you know, you have to send her, you know, with medication. You have to send her with plenty of things to eat. You have to teach her how to count her carbohydrates.

You have to -- I mean, it is a constant thing. And she was nine and I cannot imagine the challenge of having a baby or a toddler who can't tell you oh, I think I am going low. Or, you know, I am having a problem.

I mean, I think that that's -- I mean, I totally agree with you. I think that a child six and under -- that a parent -- that a whole family needs any support they can get.

Okay, so, you know, we are working to achieve the gold standard in our family. And so what does that mean? I mean, it means that you do everything you think that you should do and can do.

So you constantly read. You constantly talk to your health care professionals that take care of your child. And Kathleen is very interested in insulin pumps because for her, at that time, the long acting insulin had to be given like every 12 hours. And you couldn't sleep in if you, you know, were -- you know, on a weekend. You had to get up every single day at a certain time and have your injections at a certain time.

And at that time, she was, you know, using NPH regular and then advanced to Humalog. But, you know, you had to eat at a certain time and you had to -- you have a child who, you know, again is nine or ten years old and you say okay, you know, what do you want to eat? We have this, this and this. And so, she says okay, I think I want this and this. So you count out what you think is going to be 80 carbs. And then they sit down to eat and you know what? That didn't taste good.

And you are thinking oh, my gosh, get out the chocolate milk and, you know, she is going to go low because I gave her so much insulin and how am I going to put her to bed at night? And, you know, I will be up all night thinking about her. I will be going in and checking her blood sugar and that is, you know, that is what you do.

So an insulin pump affords you -- and again, I realize it is not for everyone, but it affords you the flexibility, which at that time you didn't really have with the regime and the different insulins.

So, Kathleen was interested in the pump. So in March of '99, she started on an insulin pump and she is a competitive dancer. And so that allowed -- you know, allowed greater flexibility and she could eat -- not whenever she wanted, but it didn't have to be just at a certain particular time; not more frequently than every two years.

But it just, you know, allowed her again to feel more normal now. And I also had a plan that, although she was interested in it, thank goodness, but if she wasn't, I was going to start talking it up because I felt like that was the gold standard.

And I wanted her to start an insulin pump to feel comfortable wearing a device before her teenage years, which body image, and if you just, you know, you walk down the street where there is any group of teenagers and the things that they wear and things -- you know, I have two people nodding and the fact that you know what it is all about.

Fashion and, you know, you don't want to be different. You want to be able to wear things that everyone else is wearing. So, I thought, you know, I am surely not going to wait until she is 15 or 16. You know, she would feel funny about it. And so, she didn't miss a beat.

You know, she wanted it and she started on the insulin pump, which has been great for her, but you have to be extraordinary vigilant. I think you have to be bright. You have to be -- you know, to be able to manage the calculations. Now the pumps have it built in where you can put in your blood sugar and if figures everything out for you.

But, you know, when we started, you know, there was a hundred formulas and you have different ratios for the carbs. You know, she has a ratio, you know, say of eight -- dividing everything by eight at breakfast, but it could be ten at lunch. But if she is going to work out, you better pump it up to 15, but if she -- you know, I mean, it is complicated. It is complicated and we -- you know, I mean, we are not brilliant people, but we are fairly intelligent and it is a challenge. I am telling you it is a challenge.

But she has, you know, managed to handle all of that and we are continuing looking for, you know, new things and she has actually taken part in a study that has a sensor augmented pump.

And so now, she is wearing -- she wears three things now. She wears the transmitter for the -- she inserts the sensor and wears the transmitter that transmits the readings to her pump, which has another separate insertion site.

You know, and we were trying on dresses for a prom two weeks ago, you know. And she said, you know, I think I am not going to wear all this stuff the night of the -- I said okay, that is fine. Because again, you know, it just comes into play, you want to be normal, but it is a lot. It is a lot to have to do.

And she would be surprised to hear what I am saying because if you ask her, she would say I'm fine. I mean, she doesn't talk about it. But, you know, I see her at times with tears rolling down because it is painful. It is a hassle, but she doesn't -- you know, she doesn't complain.

Okay. So let's talk about teenage issues. I know I have talked about them a little bit, you know, fashion and wanting to be the same; not wanting to be different.

How about driving? How about every time she gets behind the wheel, she has to check her blood sugar? I mean, you know, that wasn't -- you know, okay, that is okay for her. But I am telling you that she has friends that have type one diabetes that get into trouble and, you know, don't comply and have had accidents because they have been hypoglycemic or hyperglycemic, having very high blood sugars that, you know, have impaired their capabilities.

What about the whole issues of, you know, drinking and you know, drug use? Of course, they are issues for all teens and young adults, but it is very complicated.

So as she gets older, is it easier? I don't know. In a sense, I guess, but is it harder as a parent? Yes, maybe. I mean, you know, I still go in -- I still get up on weekends when she is sleeping in and I open the door and I go over and I look at her and I want to be sure she is breathing.

Do you think I am crazy? Maybe. But is she going to be the one that is going, you have, have that, you know, be dead in bed? I mean, I hope not. So I can never forget about that.

How about college? How am I going to send her off to college? So, wish me luck. Okay, now the cost of all of this, the cost to our family financially? I mentioned something to my husband, you know, on my way out the door. I said how much do you think -- well, we think several thousand. And you know, we ought to put a pen to it and we should do that and it will be painful to look at it.

And you know, we are very fortunate. We are very fortunate and we are able to do that. And a lot of people can’t. And those are -- you know, whenever I have the opportunity to talk about kids with diabetes, those are the kids.

I mean, yes, I didn’t mean to get emotional about my own child, but those are the kids that you are going to be supporting because, you know, they may not have the resources. They may not have an adult in the household that is capable. It takes a lot. It really takes a lot. I am talking, intellectually, emotionally. And so those are the kids that I worry about.

And Kathleen has had the opportunity to go to a summer camp for kids with diabetes and it is a fantastic experience for her. But the reason I am on that board is for the other kids because they gain so much from being around, you know, people like Maureen who are great examples.

They learn stuff. They learn how to -- you know, kids that learn how to give their own shots. And you know, it is just -- I mean, great stuff happens in a setting like that that can hopefully prevent, you know, a child becoming disabled and, you know, increase the quality of their life.

And recently, I have had the opportunity to -- I am working with an advanced nursing practice group here in Atlanta where we provide free care to homeless children and women. And I have, you know, met some kids with type one diabetes.

And, you know, I think to myself okay, you know, a challenge for me, nothing. I mean, to take a look at these families that are trying to stay intact. You know, trying to find a place to live, moving from the night shelter to the day shelter. You know, they don’t know, you know, if they are going to be able to make it from day-to-day, let alone, you know, take care of their medical needs.

So you know, this disease affects obviously the gamut. So anyway, I hope that I didn't ramble. I appreciate the opportunity to talk about my hero, my daughter. Thank you.

(Applause)

Presentation

by Maureen McGrath, Patient Participant

MS. McGRATH: Good morning. It is an honor to be able to speak to you all. I am not accustomed to speaking without PowerPoint, since I am an educator and a nurse practitioner.

My husband, this morning when I was telling him I was a bit nervous -- I usually don't get nervous because I don't talk about myself when I give lectures. He said, how much time do you have? I said oh, about 15 minutes. And he looked at me and said, what you are telling me would take about five hours.

I just want to say that Dorothy and Kathleen are, as you might imagine, some of our model patients and parents. And it is hard for me to get up here and speak about myself when I work with -- over the last 20 years I have worked with thousands of children and adults with diabetes.

And one of my theories is, family involvement is measured by the thickness of our charts and Kathleen has a very thick chart because Dorothy sends in blood sugars on a regular basis for us to review and look at and call back.

She didn't mention the clinic visits and the record keeping and all of that that goes into the ongoing care provided. And we have got a lot of thin charts in our clinic, which means we don't have a lot parental involvement and in our Dr. Becker slide -- one of those slides has adult care something essential and it really is the key component in treating children with diabetes is family involvement.

So I am putting off talking about myself.

I do have type one diabetes and this May it will be three years. I plan on celebrating and just doing that tell you something, doesn't it? If I am celebrating? It has been a long road -- a long journey. One which I consider myself extremely fortunate because I have passed by many, many souls who have not done so well as I have.

I did find out recently I had another autoimmune condition, premature graying. I kind of let my hair color go natural and my endocrinologist told me that it is an autoimmune condition and I am very proud of it. It is not very challenging. It is much less costly now than coloring my hair for the last 15 years.

I was diagnosed a week before my 12th birthday and I got very, very sick and was in severe ketoacidosis and unconscious I think probably for a few hours, woke up in the ICU on leads and wasn't sure what had happened. As a 12-year-old, I actually wasn't sure where I was and whether I had perhaps had died actually.

Obviously, I was very near death and I had an extremely rough adolescence with diabetes and I think that is what makes me the person I am today.

I loved my pediatrician and he loved me. Unfortunately, those were the days before glucose monitoring and I was a smart, bright -- very bright young woman and he just thought I was the perfect patient and unbeknownst to him I had lied to him for five years. I was afraid of disappointing him. I would give myself insulin before my quarterly lab draws so that my --- glucose looked good.

So, not only did I lie to him, I isolated myself in the sense of I didn't let my parents know that I was suffering. I was ashamed because I knew what I needed to do, which was one shot a day and urine testing, which really wasn't very helpful. But I wasn't really doing what I was taught and it was primarily around food and not being able to follow a diet.

And every morning I would wake up and say okay, today is the day, I am going to be a good diabetic today. And midway through the day, I would just kind of fall off the bandwagon and I -- despite very poor control in my adolescence, achieved a great GPA. I played competitive sports. I sang in the competition choir. And I think those were the things that saved me.

It is the people around me and none of them know that I cried myself to sleep at night, fearful of going blind and making myself go blind, but I did that many, many nights in my adolescence.

So how did diabetes change me? Well, it made me very aware of mortality -- and by the way, the first two years of my diabetes, I did everything right. That is probably what happened, is the first two years I never ate sugar. I did everything I was told to do. And in those days, they had me measuring every urine output. This is called the total --- glucose system, which I think only Dr. Becker and maybe Dr. Parks and some other pedia endos in the room might be aware of, but it was a very old system and it was not scientifically based, but you measured every urine output.

So I went to school with my little two to three cup measuring cup, peed in the cup, measured the quantity of urine, times the percent of glucose, subtracted it from my total available carbohydrate, divided it by that --- in order to get the next --- form.

I did that for two years. I turned 13 in the hospital and for two years I did that. And then I remembered the moment two years later, when I was taking care of this --- with diabetes up in Lake Tahoe in California on the West Coast and I was --- for the summer and it was just too much.

I took two --- chocolate bars off the top of the refrigerator and I went into the bathroom and I closed and locked the door and I ate the two bars all by myself and said I have had enough. And that was the first time in two years I had candy and unfortunately it was quite down hill for the next four years.

So at 19, I got religion with my diabetes and I went to summer camp, which I had spurred. Spurred? Is that the right word? No, I had shunned it, when I was 15 and my sister said oh, there is this camp. You should go to it. And I said I am not going to a camp with kids with diabetes.

I opened the brochure and I looked at the brochure and I said well, those kids look normal. I did not want to identify with having diabetes. And so I didn't go to camp when I was 15.

I wrote the two physicians, Dr. --- and I said can I be a counselor in training? But I was too young. And so, four years later, my same sister said why not be a counselor?

And so, at 19, I went to camp. And I remember I was so fearful of going off to a summer camp where I would be the only bad diabetic.

And I had so much shame and so much fear around meeting other people and not being a good student and a good athlete. And --- people would know that I was a troubled person and that I wasn't taking care of myself.

And what happened was I showed up and I realized oh, I am not alone. There is a lot of us other bad diabetics out there. And the thing that people haven't talked about is the psychological burden of living with diabetes. I think we need a psychologist here today to talk about what happens to people like me who didn't get religion at 19, who find that community. I call camp my diabetic heaven.

I mean, I found doctors and nurses and mentors and role models and other people living with diabetes, and finally realized I was not alone. I finally realized with educated help I could take care of myself. I was finally going to be honest; that I was already myself. And --- I had some severe eye problems --- that are termed iritis. I was a sophomore at U. C. Berkley at the time and the doctor said you need to have your eyes examined. And I thought I was going in to have my iritis looked at, which I had. But they hadn't dilated my pupils and low and behold I had early --- at 19 years old. My first hemoglobin --- when it came out with 17 percent --- know what that means.

And my pediatrician, poor guy, nearly had a coniption because he knew by his first objective measurement of what I was doing to myself. And he freaked out. He thought that I was this just ideal person. And so simultaneously --- and the diagnosis of retinopathy and lots and lots of morbid thoughts at that point in my life about not making it through college.

Really, I remember sitting in the stairs at U.C. Berkley thinking I am not going to make it through college with vision. My focus --- and so I again --- finally --- eyes examined and at the time I was a --- in --- I was sent to --- to a --- diabetic retinopathy and I had joined --- patient and when I graduated from --- two years later, I started working for the project and became a coordinator in the project.

And from there on, I have been I think one of the most professionally fortunate people I know. Every single job I have had has led from my experience, I have been so fortunate and I became a coordinator of that study for five years --- for about seven and when I was in my late 20's I decided to become a nurse. And so I went back to school and decided to do pediatrics. Adults were just too depressing for me. At that point, I hadn't yet still separated myself from my own illness and as a coordinator --- I was 23 years old. I was a young one. And every day I worked for people who had visual loss from diabetes.

And my mother had a very great expression, which was there but for the grace of God go I. And it became my mission in life to -- I was thinking about this. You know how people say you should have a mission statement? --- a mission statement. Well, this morning I woke up early because I was thinking about what I wanted to say, I sort of thought about that. And I think that -- you know I have been so fortunate. I have had family and mentors and this camp for 18 years that have turned my entire life around.

And I think my mission statement really became to help others through the pain, the isolation and the shame of living with diabetes. And as my colleagues know, I am the good cop in clinic.

And I often call upon my -- the doctor who I worked with who unfortunately -- is a primary endocrinologist who does diabetes in our clinic, had another engagement today, but I often call on her to be the bad cop because I have a very difficult time, really pushing my patients sometimes because I so much empathize with their experience. And that recently, I yelled at one of my patients for the first time because I was so frustrated with his family. They were not giving him insulin.

His A1C was greater than 14 percent again. He hadn't --- since his last visit and my heart is so in this, but I had no other resources but to desperately plea with this family. In fact, they had to follow my orders.

And it is so hard for me to be the bad cop as a practitioner because I so much relate to what it is like to be in their shoes, but yet I realize I never had anyone in my adolescence like me treating me. And so I felt that after having this family for over a year and really working with them that it really was okay for me to step on their toes a bit.

So my whole mission statement is to try to essentially help my patients and families see the light, you know, the light at the end of the tunnel. The light that I always saw at 19 and changed my life.

I have had diabetic retinopathy for 22 years --- had the one experience of over treatment in the right eye.

--- of improving control and I remember just laying out my slides in the light box with my ophthalmologist who I worked with iritis, Dr. --- and saying Everett, look at

these. Look at my eyes. The last seven years look at the improvement.
--- and he just shook his head and I said, Everett, this is not diabetes control. This is pre DCCT we are talking about. And --- it is hard not to see --- ophthalmologist. My ophthalmologist would have been --- absolutely that is what is going on, but he is so skeptical because the DCCT results -- I mean, the DCCT was just starting at that point.

And I remember that day, I laid them out and I said look at these, look at the improvement. And I put my A1C's next to them and sure enough it had gone through my child years. I mean, my internist and I, we hi-fied each other when I got into the tens and the nines and then the eights.

And really until pump therapy and Humalog insulin have I only been able to achieve ACE and ADA guidelines. It has been pump and Humalogs that have done that for me. And
despite lots and lots of work and those are seven and six-and-a- half percent for those of you who aren't aware of the guidelines.

Despite all this -- and I will wrap it up because I am sure it is time. Despite all this, living with the psychological --- and the fear of diabetes, we are all a bit hypochondriacal. It is a normal thing. Not only are people with diabetes a little defensive because they are constantly having to --- through the years, yes, I can eat this. I know the amount of --- in this food.

But in addition, there is a constant fear -- now living about 20 years with diabetes I decided to look around and say well, I have got all my fingers and toes and I can see. And I have been able to keep the retinopathy at bay and my kidneys are fantastic and my blood pressure -- thank God for my good Irish genes, I have great blood pressure and great cholesterol. And so I won't be facing microvascular problems, but I know the microvascular problems can still happen.

And so the hypochondriacal part is -- any bump in the road can send you --- and Ms. Jordon and I were talking earlier about issues about this, and I said what do you think these people -- what do you think of us talking about these adults like me? And she said we are going to get burnt out. And I said think harder. And she said what do you mean? And I said I don't get burnt out. I do my sugar strips every single day. I check my sugar eight times a day, usually, you know.

I said I bet your doctor --- excuse me, when they see an obstacle. When they hit a complication. And she said, now that you mention it, that is exactly -- with a few people she had thought of, she said yeah, they got diagnosed with something and they found out they had some microalbeminuria. They found out they had some retinopathy and needed some more treatment.

That kills us. We work so hard every day, every single day to keep our sugars controlled and that when something happens, which on some level we often --- and I think I can speak for --- because I work with thousands of people with diabetes --- this sucks.

That is what I tell my patients, diabetes sucks. You know, it does. But to work so hard and still find out you have got the microalbeminuria now. It is devastating. And sure enough she said, yeah, you are absolutely right. There is people who have originally been diagnosed with a micro or macrovascular complication and they fall off track again.

Standing here and talking about your diabetes takes an enormous amount of work. I try to count the number of times I have thought about my diabetes, sitting here and listening to the speakers this morning. It was impossible. I checked my sugar twice. It had gone up because I was stressed. I gave some insulin through my pump.

I thought when I get up there if I gave the insulin ahead of time, would I start getting low? Am I going to have a hypoglycemia? I have got a beating of --- rapid heart rate right now. I know that is just pure adrenalin, but --- low blood sugar. I must have thought about diabetes in that last hour 40 times.

Now it is fading. It is fading. But to try to capture that and to try to reiterate it back to you is almost impossible. And the first machination of this pump was to go through my day and how many times I pay attention to my diabetes, let alone the days when things like, you known, the checking of the blood and all this, which Dorothy went through -- both Dorothys went through and Dr. Reed.

But, like then the guilt, I didn't exercise today. The guilt, who wants to live with that guilt. How many feel guilty when you don't exercise? Well, most of us will say, yes, right?

But with the diabetes, there has been this inspiration of this is good for me, and good for my heart, and good for my situation and so then you have all this guilt along with it.

So anyway, that was a very long --- after -- even the people who are well controlled, even really healthy, productively, highly functional -- overly functional, really.

My other mission statement would have been something like because I have diabetes I will --- to each and every one of you, it has never interfered with my ability to be a functional human being.

Well, there is a detriment in that, let me tell you. I have never had a sick day until I got bit by tick in California and got a --- and then I had to have a sick day. I had never called in sick in this clinic in my entire working career until I got bit by this stupid tick.

But I have to say family support and enormous love for my family. --- but enormous support. My brother has been a board of director for our camp for 10 years. He still gives a lot of money to our camp in California. He is -- that is one of my older brothers, very inspired -- he has got a very successful business, but very inspired by my life. His contributions philanthropically to the community have been enormous.

And my mentors, I have had some amazing mentors. And once I got religion I had the physicians at camp and the physician who took over. And I have had nurse practitioners and nurses who -- the reason I went to nursing school, --- for her doctoral thesis in nursing and I was doing it on --- and diabetes.

She --- she said, you know, have you thought about nursing? And I said --- I am going to get an NPH. Thank God, I didn’t do that. I was destined to be clinician. But I have had this camp, this incredible therapeutic, wonderful environment that --- me and most importantly, --- importance, I don’t like to think about the $.70 cost to that --- strip. I just spent a $1.50 checking my blood this morning in this room.

Occasionally, when I have had low strips over a weekend or, you know, the --- gone to the pharmacy and I can’t get --- work. And I think about the cost and should I ration these strips? And should I really check this blood sugar? There are people who do that every day of their lives. Medicare only covers 100 strips a month. Medicaid only covers 100 strips a month.

Every single one of our kids -- we call in pre-authorization forms to increase the number of strips. And even at 150, I don’t -- I use six times -- easily the 180 strips a month and I don’t have to think about it. I don’t have to think about the cost of my pump supplies, $20 every time I change my set, $7,000 pumps these days.

The one I have on my hip is another one the company said we will try out. I mean, I wear the pumps the companies give me to try them out. I never have to think about costs. And I have a supportive work environment, family environment, both my immediate family now, with my husband and my extended family in California. I have been so fortunate.

And so I say that because I feel guilty sitting in front of a disability group because there are so many people out there that have not had all the stars lined up to give them the kind of opportunity and chance -- the second chance I got at 19, because I was heading the path that there but for the grace of God go I. Thank you.

(Applause)

DR. HETLAND: I would like to thank all of our speakers. I have a few minutes after 11:00. Why don't we break until 11:20 and then I will herd you back in. Thank you.

(Short recess, followed by audience questions and discussion session.)

Audience Questions and Discussion Session

DR. HETLAND: I am going to remind each and every one of you that this -- our comments and our discussion is being transcribed, such that each time any of you start talking, you need to identify yourself so the transcriptionist doesn't need to stop and look around and see who is talking. Okay? I will exempt our speakers from having to identify themselves and I will exempt myself. Okay?

First, I ask Dr. Reed to comment on one of the listing subsections for diabetes. It is on page 96, talking about recurrent acidosis and whether or not that should continue to be one of our qualifications.

DR. REED: Well, I think that probably in a limited sense maybe. But I --

DR. HETLAND: Can you speak a little bit more into the mike?

DR. REED: Okay.

DR. HETLAND: Just pull it closer.

DR. REED: Okay. As a limited sense, maybe. But I think recurrent ketoacidosis is a failure of the medical care system and also may be a psychosocial problem of the individual that keeps getting the recurrent ketoacidosis, especially getting it this frequently.

At the hospital where I --- of course, we see this all the time and it is for several reasons. Lack of money to get the insulin is probably one of our major problems. But especially, it is also used as a way of getting attention, of getting -- and this goes beyond teenagers, as I am sure the pediatricians see.

But this also comes into play in a lot of the young adults -- a lot of the young adults that we see. So I don’t think that recurrent ketoacidosis per se is a disability. I think it is a disability if we look at it in the context in which it is occurring because I think with today’s -- with what we have today for controlling this disease with the newer insulins.

And I am not one of those that think these people are going to be able to get an insulin pump, but even with the newer insulins without an insulin pump, that should not be a problem if the patient has good medical management.

And I think you have to look elsewhere to see what else is conflicting. Maybe the patient is mentally not that bright to be able to deal because, as has been stated, it is a complicated disease. You have to at least have some degree of intelligence in order to deal intelligently with the disease to prevent recurrent ketoacidosis.

And then look for other underlying diseases --- this is -- like recurring infections is probably one of the most common things that we see that brings people, who know how to control their diabetes, to the table.

So I don’t think -- as it is stated, just because they have recurrent -- I don’t think that makes them disabled. But I think there may be an underlying cause as to why they keep coming back as they are not able to deal intelligently with the disease is why they really do get recurrent and look at it in that light, but not just because of that.

MR. EIGEN: Do you have any comments?

DR. BECKER: Well, while Maureen was talking I decided that I probably left one thing off my list of disabling conditions. And that is the psychosocial impact of diabetes that stops people from taking the insulin for whatever reason.

And those people have psychological disabilities that aren't definable in the usual psychiatric literature, yet need psychosocial help. And to be able to deal with the issues if they don't have camp and mentors like we have heard about today.

And so I think that the psychosocial disability that inhibits people from getting -- and whom needs to be treated and the biggest barrier to that has been cost. I think that most insurances don't for psychosocial counseling. They certainly won't pay if somebody is not diagnosed as being schizophrenic, or clinically depressed, or suicidal.

And so if I had to do one more thing, I would add for all these things pschosocial disablement that needs therapy, that needs money to help.

DR. REED: Let me give you an example of this. We have about three patients at Grady and I think there are some people -- I have seen this over again --- Grady, you know what kind of population we deal with at Grady Hospital.

We have about three patients at Grady that come to the hospital at least every four to six weeks who are type one diabetics with ketoacidosis. And are the reasons that they are there? Number one, all three of them are homeless. They have no income basically at all. And so they run out of insulin, then of course, when they do they are in ketoacidosis.

At Grady, we call them the "yo-yo's". You know they keep coming back like a --- but it is not their diabetes per se that keeps bring them back. It is the social milieu that they have found themselves in that keeps bringing them back. So I don't think that we can just say that this is a diabetic disability. This is a societal disability.

MS. McGRATH: I do want to add to the psychosocial disability issue. Female adolescents are hospitalized at a greater rate than male adolescents. And it is -- in our world we are pretty certain -- and there have been some good papers about this as well, is that it is related to the -- actually intentional insulin omission.

And for those of you who haven't heard of this, this is a form of bulimia called diabetic bulimia. And it is actually very prevalent, much more prevalent than bulimia in the general population. And these young girls and some boys also are at risk for very early onset of renal and retinal problems.

And so, you know, one of the number one most frustrating things of a clinician is we don't have a psychologist that we work directly with. We have an on call social worker and yet so much of the burden of diabetes manifests in behavioral -- in children, in behavioral and psychosocial ways.

DR. HETLAND: Well, I am not going to be the one who is doing all the talking. I am going to look out here.

MS. KLUBERTANZ: Terry Klubertanz from National Association of Disability Examiners. One listing that hasn't been addressed that is in the book on page 96, is listing 905 dealing with neurohypophysial insufficiency and the urine specific gravity issue.

And I guess I am wondering how frequently is this type of condition present?

DR. HETLAND: Time out. That is this afternoon's topic.

MS. KLUBERTANZ: Oh, I am sorry.

(Laughter)

DR. HETLAND: We are focusing solely on diabetes this morning.

MR. SKLAR: I am Glenn Sklar from Social Security in Baltimore. Throughout the morning we have heard some terminology at various times, the

DCCT trial and hemoglobin, A1C and if you could just sort of set the stage for the impact of control and what that means in terms of long-term complications, I think that might be helpful. Because we hit these various terms at various points, but -- pretty clear there is a picture in there.

DR. BECKER: Well, I think I might be the only person I recognize in the room who is one of the DCCT investigators. The DCCT was the diabetes control and complications trial and it started in 1985.

And it was initiated to find out whether intensive diabetes therapy could prevent complications. At the time, we knew that rats and dogs and mice -- intensive diabetes therapy could prevent their complications, but nobody knew whether this was true in humans. And some people said yes, and other people said prove it.

And the reason it was initiated then and not earlier was there were two major events that happened in the early ‘80's. And the first was in 1979, A1C or glycosylated hemoglobin was discovered. And what that is, is that when the blood sugar is high it sticks to the red cells of the blood and it says there.

And it stays there for the life span of the red cells, which is 120 days. So another name for it was the test that does not lie. So it tells you the average blood sugar over the last couple of months, probably the last six weeks.

The ones that came, we couldn’t do what Maureen told us about earlier. Get a good blood sugar the day you go to the doctor because this told us what was happening over time with a few exceptions which we needn’t go into. So it really tells you the average control.

The other thing that happened was that home glucose monitoring became available, so that instead of testing zero, people were able to prick their fingers, put a drop of blood onto a meter and know what their blood sugar was and use those blood sugars as a tool to manipulate their insulin.

And the DCCT compared conventional therapy, which in those days in the United States was two injections a day and urine testing with intensive therapy, which was multiple injections a day with blood sugar monitoring.

But probably the most important thing was that in the DCCT we saw the intensive patients once a month. We talked to them once a week and we had a health tech team; not any doctors, but nurses, dieticians, and a psychologist, who were there at the beck of call of the patients all day, all the time, day and night.

Conventional therapy, we saw the patients every three months and they -- we were available to be called by them, but we didn't initiate anything. So it wasn't just multiple injections, it was really intensive therapy.

At the beginning of the study, I didn't really, honestly know how I wanted it to turn out. And I apologize for the people with diabetes in the audience because I wanted it to work because I wanted to be able to prevent complications.

But on the other hand, I knew what hard work it would be and that if people failed, they would feel like Maureen told us this morning, that it was their fault and the guilt when they had complications would be absolutely huge.

Well, it turned out that intensive therapy works. And not only does it work -- and we have in --- in Allegheny County on a epidemiologic basis that the mortality rate has dropped significantly since the results of the DCCT came out. And this is probably true around the world. And you probably can prevent complications and prevent or delay death.

And the other important thing was it is never too late. So even if you have somebody who has really poor control if you improve it, the outcome is better than if you don't.

DR. REED: In addition to the DCCT, which was purely a study of type one diabetes. And I would like to also draw your attention that 95 percent of all diabetes in the world is type two diabetes. And so that is what you are going to be dealing with most commonly.

There were a couple of studies that were done sort of parallel what had been done in DCCT. The United Kingdom prospective diabetes study, which was done in adults and in type two diabetes, and another one called the Kumomoto study that was done in Japan with a similar age group, which really showed that intensive therapy in type two diabetes did exactly the same thing.

Not only did it prevent the development of the microvascular complications -- and I will define that for you. We are talking about the eye complications and the kidney complications and the neuropathy that develops in type two diabetes.

But it also had a profound effect upon macrovascular complications. That is the heart attacks and the strokes. By intensively treating type two diabetes in the adult you could reduce all of these by statistically significant amounts in preventing the complications for the disease.

So again -- but intensive treatment --- under the very same things that you are going to have to evaluate in the future. And it has been demonstrated scientifically that this work in both type one diabetes with the DCCT and the United Kingdom study in type two diabetes, and the Kumomoto study in Japan in type two diabetes, it works. But you have to be obsessive/compulsive about it to get the intensive therapy that one needs and this is the one thing that we have had the most difficulty with.

And actually, educating diabetics -- you know, you can write all the prescriptions in the world that you want, but it takes two to tango. And I consider the management of diabetes is a contract between the physician and the patient. And if they are children, it is a three-way contract and that is probably why I don't like dealing with children because I don't like dealing with their parents.

(Laughter)

DR. REED: But it is a contract between the patient and the physician. And I think that we, as physicians, have to understand the fact that unless the patient cooperates, you are never going to get the results that we are all striving for.

DR. PARKS: Dr. Parks. I just wanted to point out one --- area of that and that is that in many ways the treatment of -- the optimum treatment of diabetes has become so complicated that the general practitioner, pediatrician, and the internist has, over the last 10 years, done more and more referrals to specialists in the area.

And it has really become a team operation and we have seen the impact of that shift in that “I really don’t have enough” people trained and physicioned to take care of the demand.

And the teams that do exist are constantly frustrated by being unable to take that next step of prospectively contacting, actively contacting the patients. We still are in a position -- even as a treatment center, we are dependent upon the families to contact us for the most part. And the ones that do and have the charts, so-to-speak, are the ones that are buying in.

But there is still a large group that are under-served because of economic constraints, both on their -- well, on their care system in general and on the families in particular.

DR. BECKER: Can I just add to that? Because people have to travel a long way, have access to telephones, fax machines, et cetera, that is -- another cost of that is so often is not factored in. So not only is that all the equipment and the --- attached with it, patients need subsidies to get to the health care team, to get to a telephone, to get to a fax machine, and be able to pay for their long distance calls.

And we have a problem in that our hospital stopped paying for our 800 number because it became so expensive for them. And the patients are not calling us because they can't afford the long distance calls.

And so, I think that is something when we factor in financial needs to SSI, we would be able to prevent a lot. And if you send the patients just -- once they have all the complications, it is not too late. I say it is not too late, but it would be nice to get them earlier so we could prevent the protein in the urine in the first place.

MS. McGRATH: I want to add something, which is as a healthy adult living with diabetes for 30 years, I still have a yearly ophthalmic exam and because my eyes are so good, I only go once a year and that is pretty typical if you don't have problems. Who have twice yearly dental visits, which everyone should be doing. You have your ongoing primary care and then your ongoing gynecologic care.

If you have any -- you have your annual labs or more. You know, just maintenance. In addition, you know, if you have any problems -- you have podiatry, ---, more frequent visits with ophthalmology. Am I forgetting -- I mean, this is -- this is with the luxury of good health care insurance, working almost full-time, fitting in all of these ongoing maintenance. And this is a very difficult maintenance schedule for even people with full health insurance.

And then you have to consider what happens when they have coinciding ---

DR. REED: Could I just put some of this in perspective? Because I think that we really do need to. You need to look at diabetes from its national or global perspective in this country.

Diabetes -- there are approximately 20 to 22 million diabetics in the country. I bet that about 95 percent of those are type two diabetics. And if you look at the prevalence of diabetes -- or if you look at how it is distributed in the country -- you know, this is what I consider more than an equal opportunity disease.

You don’t have to talk about equal opportunity because everybody has a tremendous amount of opportunity to develop this disease. It is twice as prevalent among the African-American population as it is among our Caucasian counterparts.

It is four times as prevalent among the Hispanic population as it is among our Caucasian counterparts. And it is about six times more prevalent in the Native American population than it is among Caucasian counterparts.

And if you look at the economics of each group, then you can see that this is a real --- and we have seen here just the tip of the iceberg. For people who have fantastic health care insurance -- Maureen has a fantastic system and every diabetic should be so lucky to have this.

But you have to remember that you are talking about two to three percent of the population of this country that has that type of health care that can be managed as well as she would. So she will probably outlive most of us, because she has great care for so doing.

But the majority of the diabetics out there, be it children or adults, do not have this type of care. And I think when you start writing regulations about how you are going to quantify disability, this has to be a component part of this.

Because, you know -- and I am not asking you to fix the health care system in this country because I think unless you take a giant vacuum cleaner and suck it all out and put in a new one, you are never going to fix it. But nonetheless, it is a part that plays in what you are trying to do when rewriting these regulations.

DR. HETLAND: Well, I think I should say that in a pediatric population qualifying to apply for SSI, the family has to have limited income.

Parents who are working, who have a monthly income are probably not going to get through the first step -- or get into the process because they won't qualify for financial reasons.

I am curious, what does -- so we are talking about a Medicaid population. What is Medicaid covering right now in your states and what is it not covering?

MS. McGRATH: I can speak to Georgia. Georgia provides at base three strips a day, 100 a month. They cover insulin as needed. They have to write dosing on all of the prescriptions now in order to get a very precise amount. So the extra vial at school -- what do we do, James? We fudge the dosing because we need them to have -- am I horrible about breaking the laws here?

These new dosing diagrams are new in Georgia and so we need our kids to have a vial of insulin at school, but yet, that means two vial a month, so Medicaid will cover. So far, we haven't been called on that. They cover syringes. They cover all the essentials.

They will cover insulin pumps. It is just a more rigorous process. I must say that we are fortunate that we work with children -- my families that fall through the cracks are the families that don't qualify for Medicaid. Peach care is the second tier. The third tier is Children's Medical Services, which is also in most states.

But people that fall through the cracks are families that make too much money for any of those, but yet, they can't pay their $800 a month premium. But Medicaid covers all the basics. What our staff has to do every single time we have a Medicaid patient, who is already giving $106 a month, we call in and we get prior authorization and we increase it according to the age of the child.

Most kids can get by with 150 strips a month. The toddlers, we get 200 or 250. We haven't had any denials, have we on those? So we have been fortunate so far, but things are getting tighter. The dosing is new. The strip restriction is still something that I get very frustrated with.

I tried one day to go all the way to the top through the phone system to try to get to talk to someone, to argue and it was joke. I mean, I think it has to be made at a policy level. That is going to be my next job is lobbying.

Oh, sorry. Yes, thanks, Jim.

Ketone strips are not covered by Medicaid. I don't know about state-by-state, Dr. Becker. Ketones are dipping the urine to -- when a blood sugar is high, we want to know if there are ketones that are being spilled in via the --- because that tells us that there is a state of insulin deficiency and that tells us whether the child is just having a high blood sugar because they ate too many carbohydrates and didn't get enough insulin or they are actually insulin deficient and are at risk for going into diabetic ketoacidosis and Medicaid does not cover those strips.

So fortunately, they are a cheap item relative to other items, but we have to ask our families to pay for those or we give them a few in clinic that are foil wrapped donated by the drug companies. But that should definitely be covered because it is a preventive device.

DR. BECKER: It varies state-by-state and it varies within the state depending on where they are at that moment in time. And in Pennsylvania it varies also to which insurance company is supporting the Medicaid.

We have -- Medicaid patients can go through three different insurance companies. What is interesting in Ohio and West Virginia is they will pay for a pump for $7,000 and all its supplies, but they won't pay for an insulin pin, which is what, 28 or $30?

And they will pay for certain insulin analogs, but not others. And so there are limitations according to the rules that somebody set -- that was set by somebody not doing, I guess what you all are doing. They didn't look at the logic of the parameters they set. And then, somebody has to apply those parameters, so they end up paying for the more expensive things and not for the cheaper ones.

But I would like to reiterate what you said, that people who are in the greatest difficulty are not the Medicaid people. They are the people who earn $9,002 where they can't afford health insurance and if they do it is minimum insurance and they can't afford the cost of diabetes. And those are our biggest problem and those are the hardest ones to get SSI for.

MS. McGRATH: I also counsel my patients when they are turning 18, 19, that they better be entering college or looking for jobs with group health insurance. I mean, Medicaid cuts off at 18 years old. Peach Care cuts off I think at 19 and CMS cuts off at 21, so part of my job as a clinician is to help prepare them for the future and they cannot live with diabetes without health insurance because they are going to be like the patients that end up in DKA at Grady.

DR. REED: These are the patients that I term the medically -- the working poor and they are probably one of the largest populations in this country. I realize that is a politically "incorrect term" but I think most of the people that I have dealt with know that I don't have a politically correct bone in my body.

(Laughter)

And so I am telling you it is the working poor that are really falling through the cracks. They have absolutely no coverage up or down for this and they are getting lost in the middle. And they are the people that are probably going to be doing most the coming to you for this, but trying to place that group, you know, and there is a dollar amount in between which people work that they can't afford health insurance. And they are too rich for Medicaid, but they are too poor to have health insurance and they are the ones that are falling through the cracks.

DR. BECKER: I think you can see, we all feel very passionately about this. You can't get every child age 18 to go to college. Yet, very often that is the only way they can get medical support. And the kind of jobs that 18-year olds get without going to college usually don't pay for health insurance.

So again, this is something that we know in Pennsylvania -- when we discharge the children from our clinic, they get lost. They don't see anybody until they get their complication.

DR. REED: You know, and this goes across the board, for example. I guess the people that invite me -- and I spent a considerable amount of my time in the U. S. Army and their rule is just as bad. If you have children, if they go to college, you know, they will help you support them until they are 23, but after that they are out on their own. So you have to sort of encourage all your kids to go to college, so that they can get a job, so they can get health insurance once they pass 23 years of age. But we still have totally forgotten that forgotten group of people in this country that probably need our help more.

And I am not asking you to solve that, but I think that is something that you have to take into consideration when you go through these evaluations that you are clearly -- and you are going to get more of them.

As I stated earlier, you know, type two diabetes is something that, as a fellow, I don't think I ever saw one, except maybe on occasion in a --- but now I am getting calls every day from pediatricians who have seven, eight, nine and ten year olds who are coming down with type two diabetes.

They are going to be getting your complications 10, 15 and 20 years later or earlier than you are getting these complications now. And I think it is something that we are going to have to prepare for.

DR. HETLAND: I have another question that, hopefully, will prompt a little bit more interactive discussion. The child who is under the age of five -- we have the concept of what we call medical improvement whereby for anybody who qualifies for SSI or for disability, every three years we have to go back and review the case and find out has there been medical improvement?

And if there has been medical improvement, then that, by law, is an indication to cease benefits at that time. For the child who is under age five who then turns six or seven and it is time for their review, how can we say that there has been medical improvement? Anybody?

DR. BECKER: Lynne, I think you need to help me on this, but I would say that for what we have to do, what we are looking for is medical maintenance. And we should not be waiting until somebody is in poor control before we intervene.

We need to maintain them at the best that that family can possibly be because it will save our country huge amounts of money at the other end and keep them in the work force.

DR. LEVITSKY: That is difficult because obviously --

DR. HETLAND: Identify yourself, please.

DR. LEVITSKY: Oh, I am sorry, Lynne Levitsky. I am another pediatric endocrinologist who is speaking this afternoon. It is a difficult question because like the definition of disability in diabetes, it more relates to a total family disability than to a child disability.

So that medical improvement -- the terminology is difficult for us. One might better talk about available resources. I know that Dr. Becker and I talked about this beforehand and the sense was that if there are limited resources within SSA, then they should best be spent to support the families who don’t have the outside resources that might be available through schools.

So we are looking at whether there are other available resources. For instance, is there a school nurse or a system that can support the child during the day might be a better way to look at it than medical improvement, but to look at resource improvement.

And in some areas of this country there may not actually be resource improvement with the start of school.

Dr. Becker and I happen to live in relatively privileged states in that regard.

DR. HETLAND: Barry, I am sure you have something to say.

MR. EIGEN: (Away from microphone)

MR. WAITSMAN: Rick Waitsman, Administrative Law Judge and also a parent. The statute and the name of the program is a disability program and particularly when we start with children, as we go through the application the goal is that you become qualified and defined as disabled.

But as a parent, you are an advocate for your child and want them not to be derogatorily labeled or limited in activity, just daily living or expectations. And, you know, it is a pretty big label to say to someone that is a child that, you know, our expectation for you is you will never be able to hold a job, no matter how simple it is.

And I was wondering, as we talk about it, if we could do a different program, would it be better to have more of a medical model and your goal is to get the most out of the child. And so that you have more of a medical model in a treatment plan that has few limitations and you won't possibly be sending them the message that if you have complications of acidosis every two months, well then you qualify for a check.

But we want the person to go to the physician, get treatment, be as compliant as possible and turn it around so that it is -- get the person and the family as early as possible and go for the best outcome possible.

In my understanding we are running some pilot programs and people apply if what they are really looking for is say, a surgery or some kind of intervention that will get them back in the work force is kind of take them out of the system a little bit and provide that kind of care. So I would appreciate any comments.

DR. REED: I think that what you are saying -- and I totally agree. You were saying an ounce of prevention is worth a pound of cure. And we have not really looked at what that pound of cure is costing as it relates to what that ounce of prevention would cost.

And I think we need to put -- when we start looking at what is going to come down in the future as far as disability is to look what it is that I can put into this up front to prevent that astronomical cost that is going to come to you down the line.

And the systems that we have in place clearly do not address that as a viable alternative. Because it is all patterned after what the health care system is like. And we have a fantastic sick care system in this country, but we don't have a good preventative health care system, so we have a half health care system.

So you need to talk about how are you going to prevent this child from being a disability burden later on and it will cost you a whole lot less if you do this now than it is going to cost you later when this child becomes a disability burden.

DR. HETLAND: I will rephrase the question. How is a six-year-old diabetic who might be applying for the first time different from a five-year-old if we have different criteria?

MS. McGRATH: I think you have to consider the school environment from -- here in Georgia -- I am from California and I hope things have improved out there, but in Georgia, we have a fairly good school nurse population, so that if there is a child with a chronic illness in the school environment, so far the state are getting nurses into those schools.

So you have to look at the school environment -- and I really like what Dr. Becker said about Finland and what they do because I do really think that our kids who are under five, the ones that do the best are the ones that have 24/7 coverage by their parents. When you send them to preschool it opens up an enormous can of worms because preschools are exempt from 504 protection.

Don’t ask me why. This is a loophole I have spent weeks on last year trying to get coverage, but a shot given to my preschool or in the Headstart program and could not get it done and I gave up. And I did go to the top of the state and that when I found somebody who would actually listen to me and said, sorry, we are exempt. And I still don’t understand why because they are federally funded.

So you have to look at what the school provides in terms of medical maintenance is what Dr. Levitsky -- I think the term -- Dr. Levitsky -- you said medical maintenance. Because if they have a trained professional in that school who recognizes hypoglycemia -- who recognizes hypoglycemia, DKA prevention, knows how to check blood, manage a pump, gives shots, then you have a child who has been transferred into the care of a system that can take care of their diabetes. This is not health, is that --

DR. BECKER: This is the discussions that we had preceding this. I am the spokesman for a number of my colleagues and as I said, when I gave my talk, we quickly agreed there was really no disagreement around the country. And part of the reason for the preschooler is at least part of the day in many, but not all schools, another adult can look after the child.

The child at six or seven still needs care and somebody still needs to observe them all the time. But a child at six or seven is more likely to be able to say I am not feeling well. I think my blood sugar is low, than a four-year-old. Although, some of my four-year olds can, but the two-year olds -- I have had one three-year-old who said there was volcano in her tummy.

It is the cognitive ability as the child get older helps. There is a major issue of schools taking responsibility in the United States and we are dependent on -- I think the American Diabetes Association is working extremely hard in trying to prevent schools from advocating that care. I think it will happen and that is why we thought it would be optimistic that something will turn out right.

And, you know, our health care system -- the school age, we need to look after the preschoolers because of the limited resources. And if we didn't have limited resources, as I said at the beginning of my talk, it should be every child with diabetes.

DR. REED: Could I just have a sort of different twist on this. I think the simple answer to your question is that the six-year-old is different because he is going out of the control of his parents. And it is where is he going out of the control of his parents who has had the time, and the energy, and the desire to take care of him? He is going into an environment where you do -- you have to evaluate what environment this child is going to when the child leaves his parents.

And that -- and, you know, we can talk about what we have here in Georgia, and granted -- you know, one of the biggest fights in this country in the education system is whether or not school nurses are going to remain in the public school system.

So you cannot -- if you are going to look at this from a nationwide standpoint, you cannot look at it from what they have in Georgia -- here in Georgia, that is a little bit more ideal than what is had in probably the rest of the country.

So you have to look at the environment that the child is leaving when he leaves his parents. And what environment is this child going into after he leaves his parents' confinement? Where his parents were caring for him, who is going to care for him now?

And that is the difference between the five-year-old and the six-year-old. They are leaving the comfort of an environment where he has had loving care and going to an environment where that may or may not exist.

DR. HETLAND: Dr. Levitsky?

DR. LEVITSKY: Lynne Levitsky. Dr. Becker, if you have said this before, I apologize. But Dr. Hetland called a while ago and asked this question of a number of people. I was one of them. And I said to him well, you know, if you really look at the criteria for disability in childhood -- if it is requiring the constant attention of others to maintain health, all children with diabetes fall into that category.

Now, they didn’t when our management was simpler and we had less understanding, but now they all fall into that category. And I certainly have many patients who are well enough off to have a parent either switch to part-time work or stop working entirely, whose parents will go into work and give injections at lunch time, who are constantly there, who carry cell phones so the teachers can call them all the time.

But I also have many other patients, where a single parent or both parents are striving desperately to keep their heads above water and keep the payments on the trailer. And those people cannot do that and you can tell by looking at the level of hemoglobin you would see which people they are.

And that is a terrible inequity in care for kids with diabetes in this country, which is why the question has to be broader than a cutoff when we -- we are trying to be helpful to you all because we know that there are limited resources for this kind of care in this country and unlimited resources for other things. I will get politically incorrect also.

And because of that we try to say okay, well maybe just the younger children need this. But the bottom line is that the way we manage diabetes today properly, every single child with diabetes requires constant adult supervision. And when people ask me when childhood ceases, I usualy tongue-in-cheek say, 30. But certainly, it takes a long time, probably through adolescence before kids can really take on this care themselves.

DR. BECKER: The last slide I showed of my football player, his mother still phones him at 3:00 every morning to check his blood sugar. And she allowed me to tell this, so I think, as I said, we all agree --

DR. LEVITSKY: He didn't, but she did.

DR. BECKER: He did too. He did too. Because the family involvement is important. And what we should do is allow people to do what is best for their kids. You have heard a few times that most families cannot do that.

MS. McGRATH: It doesn't stop at a certain age. Just yesterday, one of our star football players in the State of Georgia just scored two winning touchdowns for the play off, came in and he went to 11.9 percent. And --- is not my patient, but I --

DR. HETLAND: How bad is that?

MS. McGRATH: Terrible. You are A1C -- in the DCCT the protective A1C was around seven percent and the goal for ADA is seven in adults, so six-and-a-half for the ACE.

But in children we have new guidelines through ADA and that teenagers should be seven-and-a-half or less are the new guidelines.

DR. HETLAND: So 11 is pretty bad?

MS. McGRATH: Terrible. And every one percent above that is a direct percent increase in the risk of complications. So this is not my patient, but I -- with my own diabetes I take a little license and I looked at him and I said -- I said to the mother, you need to start giving him his insulin again.

And I said to him -- here he is, you know, a strapping six-foot-three, big guy. I hit him on the shoulder and he had big muscles and I said this is ridicules, you are not getting your insulin. Your mother needs to be giving you insulin.

And he looked at me and he said I can't do that. And I said why? Because you feel like a baby? And he said well, yeah. And I said you are not getting your insulin. Your mother needs to give your insulin.

And I remember him standing in the hallway saying you can't jeopardize -- his career may be -- I mean, he may go and get college scholarships. He is an excellent player. He may get college scholarships based on his career here -- his football career.

And I said this can't happen. This is a 17-year-old kid. It is a family illness. When my kids come in with repeat DKA, the most common reason in childhood is lack of adult support and supervision.

DR. HETLAND: Mr. Sklar?

MR. SKLAR: Hi, I am Glenn Sklar from Social Security in Baltimore. What has been so fascinating about this panel is that you are not only challenging us to slightly rethink this particular listing, but to completely rethink how we do this listing.

Frankly, for us, it is not a complete surprise. We have done other outreach sessions like this on different topics. For example, the pulmonary system and childhood asthma where again, is the impairment itself the real issue? Or are folks coming into Social Security essentially looking for the health care piece for which we are a gateway for again, if you qualify for disability benefits? SSI is the gateway to Medicare for adults, for children. SSI is the gateway for Medicaid.

So for us, it certainly sounds like we have to go almost back to the drawing board and really rethink this listing from the ground up, based on what we have heard from this panel, which for us, is an interesting challenge.

But considering that this listing is possibly quite old in fact before DCCT, before issues of control were brought to bear. Plus, the further complicating issue of access to health care with type two, which again, politically correct or not, we have heard your message loud and clear that we can’t forget about type two and that there are real issues there that we need to focus on regarding access to treatment.

So this is going to be really difficult and challenging for us, but I would have to say we are certainly up for the challenge.

DR. BECKER: Can I add to your challenge? Because we have another politically incorrect people here. And as we have discussed this, we heard all the time that the changes that need to be implemented would take an act of congress. And I would say if it takes an act of congress, so be it, let’s do it.

MR. SKLAR: Just a quick reply. What we did mention that we are, at Social Security, looking into different demonstration projects where we have provided interim health care benefits for certain impairments on the theory that by, of course, an ounce of prevention -- and that certainly we don’t want to set up individuals for a lifetime of benefits.

So perhaps, it makes a little bit more sense -- much like private insurers are doing now as well, where they actually provide interim health insurance packages because they feel it is in the interest of their -- of the insured.

So we are experimenting with a lot of different ideas. So the things you have mentioned today are something of an overlay to what we have heard with other panels like this, but very interesting and a challenge for us.

DR. HETLAND: I would like to thank our panelists.

(Applause)

DR. HETLAND: Now, we are going to break for lunch and we will reconvene at 1:15. And if there is time this afternoon, which I think there will be, we can continue some of these discussions also.

(Whereupon, a luncheon recess was taken.)

AFTERNOON SESSION

DR. HETLAND: For the afternoon schedule, we are going to modify it slightly from what is printed. We have two speakers. The schedule says we will take a break right after that. Instead, we will go right after the two speakers into our discussion. And I don't think anybody is going to cry too much if we get done a little bit earlier this afternoon.

It is my pleasure to introduce our two speakers this afternoon. First, will be Dr. Lynne Levitsky, who is a Professor of Pediatrics at the Harvard Medical School. She is a Pediatric Endocrinologist and she is Chief of the Pediatric Endocrine Unit at Mass General Hospital.

Our second speaker will be Dr. Eric Orzeck. He is an Associate Professor at the Baylor School of Medicine. He is the former President of both the Houston Chapter of the American Diabetes Association, as well as the Houston Society of Clinical Endocrinologists. He also is here as a representative of the American Association of Clinical Endocrinologists. Dr. Levitsky?

Disability in Childhood Endocrine Disorders

by Lynne L. Levitsky, M.D.

Pediatric Endocrinologist

Associate Professor of Pediatrics, Harvard

Pediatric Endocrine Unit Chief, Mass General Hospital

DR. LEVITSKY: Thank you, Dr. Hetland. I am going to be talking and using this as a bit of a Billy Pulpit for the children who are cared for by members of Lawson Wilkins Pediatric Endocrine Society as well.

(Slide)

My outline will be, first of all, to do something which we did all morning, but I thought I needed to reiterate, which is to plea for a change in diabetes coverage. And then to do a very technocratic kind of critique of what exists now for coverage of other disorders aside from gross disorders in pediatric endocrinology. And then to make some suggestions for change in coverage.

(Slide)

So I don't think I really need to go over this again. I did it a bit before, but the most common and disabling disorder that we really have in pediatric endocrinology is type one diabetes.

And techniques to maintain blood sugar control now are so labor intensive and complex that I really would implore you, as many of us did this morning, to consider expanding coverage with SSI for these children.

(Slide)

So now I am going to become quite technocratic -- you heard my human side a little bit before, and just go over the present criteria for the existing guidelines. And the first of them, 109.02, is hyperthyroidism. There are some things in the diagnostic list which are not really used very often any more and usually today we only use an elevated free T4 or T3; not the T4 and T3 resin uptake that were described some years ago, but sometimes they are still used. ---

uptake is not used for diagnosis of hyperthyroidism any more and probably needs to be removed.

(Slide)

The other issue is the discussion of the handicapping nature of hypothyroidism and in the reds, as they are now written, --- the hypothyroidism is an IQ of 70 or less or precocious puberty or growth impairment and things like IQ of 70 or less really stands on its own as a handicapping condition.

It certainly can be a part of congenital hypothyroidism, but it doesn't necessarily needed to be treated like that. And I am unclear why growth impairment --

VOICE: --- (away from microphone)

DR. LEVITSKY: Oh, I am so sorry. I am unclear -- I am from New York originally, although I was born in South Carolina and that always causes a problem. I am unclear why growth impairment of the usual sort handicapping and it is unclear how precocious puberty is handicapping in regard to the criteria of requiring constant adult care.

(Slide)

The next on the list is hyperparathyroidism, which is a pretty rare disorder in children, 109.03. And right now it says repeated elevated, total or ionized serum calcium or elevated serum parathyroid hormone -- and I would suggest that be changed to "and" elevated serum parathyroid hormone in order to make the diagnosis of hyperparathyroidism.

(Slide)

109.04 is hypoparathyroidism or pseudo-hypoparathyroidism. And right now the two indications which would be severe recurrent tetany or convulsions, which are unresponsive to prescribed therapy or growth retardation.

Once again, growth retardation is an issue which Dr. Parks will address tomorrow when and I am not sure how that fits in. When I come up with my recommendations, I will point out that in general recurrent tetany or convulsions unresponsive is to prescribe therapy is like recurrent diabetic ketoacidosis. And perhaps we need to think about this in a different way.

(Slide)

109.05 is diabetes insipidus. And the documentation of diabetes insipidus in the old regulations reads “documented by pathologic hypertonic saline or water deprivation test and one of the following.” And what I would suggest this be changed to is “documented by water deprivation test.” The hypertonic saline test is almost never done today and when it is, it is done in a research environment. It isn’t necessary to be done to make this diagnosis at all. And then keeping in intracranial space occupying lesion before or after surgery if this is handicapping when the person is done.

But adding unresponsiveness to vasopressin or vasopressin analog, because in the original --- responsive to pretressant (sic). Or growth retardation, which is listed all unresponsive hypothalamic thirst center which chronic or recurrent hypernatraemia, I would add hypo and hypernatraemia.

And I can leave a set of these slides for people who need to look at them. And the decreased visual field attributable to a pituitary lesion that is there. I really don’t know exactly what that has to do with making the diagnosis of diabetes insipidus, but it is there.

(Slide)

The next on the list is 109.06, which is hyperfunction of the adrenal cortex, primary or secondary. And the diagnostic criteria in the old regs are basically things that we don’t use much anymore.

The first is elevated urinary 17 hydroxy --- steroids or 17 ketogenic steroids. And you are hard pressed to find a lab who will run those for you anymore. So I would change that to elevated urine free cortisol or nocturnal serum cortisol -- sorry that is a typo. Or nocturnal salivary cortisol and failure of suppression with -- and then there are a couple of choices, dexamethasone, CRH test or low dose dexamethasone or -- because these tests are changing all the time and they are kind of a moving target, other standardized tests of hypercortisolism with documentation.

(Slide)

Now, the next of these is 109.07, which adrenocortical insufficiency -- and if you want to use this as a criterion, recent recurrent episodes of circulatory collapse will work. Once again, this falls into the recurrent DKA theme though. It is not something that should happen.

(Slide)

The next of these is the lathyrogenic hypercorticoid state, which is 109.09. Diabetes came just before that. And I have changed this a bit too. As it is listed now it is with chronic glucocorticoid therapy resulting in one of the following: (a) osteoporosis -- and I have modified osteoporosis to read with fracture or chronic bone pain.

And then growth retardation which will be discussed tomorrow. Diabetes mellitus, myopathy and emotional disorder, as described before. And any of those can be severe enough to fall under the appropriate criteria.

(Slide)

I have left -- the next one is 109.11, which is listed as adrenogenital syndrome. I would hope for the sake of our patients that we can change the terminology on that, and change it to congenital adrenal hyperplasia. It has not been adrenogenital syndrome I think since the days of Dr. Lawson Wilkins and perhaps we should change that a bit.

And then the list of complications, as described, can certainly be considered, but once again, in general, these complications are like the complications of recurrent diabetic ketoacidosis.

Management of these children requires supervision with medication, but not every 20 minutes. I mean, they require medication two or three times a day.

(Slide)

109.12 is hypoglycemia with recent recurrent hypoglycemia --- coma and I didn't comment on that. I will, because I think that we need to support treatment of hypoglycemia, which doesn't require going into coma and becoming -- having cerebral dysfunction.

109.13 is the last one and that is gonadal dysgenesis turner's syndrome and I don't really understand how this fits in because, really, they have multiple impairments if they have them and those should be treated as their individual impairments.

(Slide)

Okay. So these are the sort of technical lists. Then general criteria, turning back into a human being and a physician here. First of all, I certainly concur that medical care in the United States is patchy and inadequate for many.

And children with any of these disorders -- they are all life threatening disorders -- or most of them are life threatening disorders and, if they don't have access to medication and medical care, will die. And I certainly have seen children who have been in that situation, so we have to reflect the fact that children who live in families that are very poor or who live in rural areas may need support just so that their families can get to the doctor and get these children some help or get into that path to allow them to get medication.

But basically, the guidelines hypoparathyroidism, adrenocortical insufficiency and congenital adrenal hyperplasia are very much like the present guidelines for diabetes in children. And they basically are rewarding failure to take medication rather than supporting families who wish to take care of their children properly.

And in general, this means that the families need access to appropriate medication and access to emergency medical care. So that there will be some families who are sorely pressed and stressed, who will need this kind of help even if their children seem to be doing well because they are doing a good job at the sacrifice of their ability to function appropriately as a family to work for instance.

The guidelines for hyperthyroidism may reward failure to take medication or treatment. There are some people with hyperthyroidism who take a long time to come into control after radioactive iodine therapy, who might still fall in this category and would be severely disabled during that time. Older adolescence for instance.

(Slide)

And there are some disorders which require intensive adult supervision and management. I actually sent out some email requests for --- about which of those disorders they were. These are disorders which require care analogous necessary to take care of children with type one diabetes. They are very rare in general, but you can’t exclude them. So I would like you to consider these specifically.

The first of these is diabetes insipidus or the syndrome of inappropriate antidiuretic hormone, SIADH, in children who are not in control of their fluid intake. And that means very young children or children receiving their fluids through a gastric tube or children who have disordered thirst mechanisms at any age.

Those children are at terrible risk and need to be very carefully cared for and require the same kind of parental supervision as children with diabetes mellitus type one.

The next group of children would be children with hypoglycemia who require frequent blood glucose monitoring or continuous feedings or administration of --- medication which needs to be given very frequently, every six hours in some cases or four hours even, which would be at this point atriatide (sic).

Other children who have a hypoglycemia which is controlled with oral medications with rare episodes of hypoglycemia should not be at great risk. But the kids who cannot be controlled and require these frequent monitorings are at great risk.

(Slide)

And then finally there are disorders that may fail appropriate medical therapy and they have to be considered as well. Examples would be hyperadrenocorticism because of malignant double production of cortisol or aldosterone or --- a releasing hormone or ACTH. There are people with very rare and unusal tumors where medical therapy has not been sufficient to alleviate those symptoms.

Another very rare one would be hyperparathyroidism with hypercalcemia, a terrible bone disorder secondary to malignant overproduction of parathyroid hormone and hyperthyroidism, which for reason -- and this can happen, is not amenable to thyroidectomy or radioactive iodine treatment. But these are very rare conditions.

(Slide)

And then exogenous hypercortisolism should be considered as a disability if it leads to functional impairment that is severe enough to prevent normal activities of daily living and requires adult supervision. And this can range from severe osteoporosis with pain or fracture to severe emotional disorder which requires that kind of support. So those are my suggestions for the things which very pragmatically look like they should be covered.

(Slide)

There are other rare disorders which may impair function, but they impair function by affecting intellectual function and can be looked at using other criterion. And those would include things like thyroid hormone insensitivity where people have higher thyroid hormone levels, but intellectual --- adrenoleukodystrophy affects the central nervous system chronically and can be evaluated because of the affect on neurologic function.

(Slide)

And finally, the young children with diabetes. That is really where we need to put our attention. I would make a plea for individual consideration as other people have done at this meeting because any one of these disorders, in special circumstances, may require supplemental Social Security input.

If you have a child who has a single parent who has to work very unusual hours and cannot manage his medication care, the effective SSI may be able to keep them partly in the work force and yet allow their child to live a normal life. So individual consideration is most important. Thank you.

(Applause)

<u>Presentation</u>

by Eric A. Orzeck, M.D., FACE

Associate Professor, Baylor School of Medicine

DR. ORZECK: Thank you. We have heard comments concerning the actual disease processes and how we, as endocrinologists or individuals with the disease, need to come up with certain guidelines.

But I would like to spend about a minute or so telling you why I am here. I am delighted to be here and my background as to why I think I can kind of give some other unique perspective.

I was born on and lived on an Indian reservation in Washington State for many, many, many, many, years. My father was my an itinerant physician. He rode the circuit in Western Washington, if you are familiar with Olympic National Park and the Forest.

And after a while, I was home schooled because my mother was the school marm, if you will, on the reservation. I went around with my dad. And sometimes we rode on horseback and sometimes in a car. A lot of times there weren't any actual roads and during the rainy season, which is about 260 days of the year up there, the dirt roads to the Indian reservations on the coast were impassable by car.

And so we would get into all these philosophical conversations. There is not much to do when you are driving around with your dad. He had me sharpen his needles on his wet stone and you could only do that for so long without actually getting bored.

So it became apparent that he had a real depth of knowledge as a real family physician. He would deliver babies. He did not deliver me. He didn't get there in time. And the woman who did deliver me, by the way, is still alive and we meet once a year when I go back up there. He would take out tonsils. He would do everything under the sun.

And his biggest mentor, if you will, was Osler. Those of you who don't know, he was the great physician at Johns Hopkins in the late 1800's and much of what he wrote in the 1920's and '30's was still extant when my dad and I were out treating people in the '40's, because he had no medicines that worked.

He was thrilled that he had just gotten some penicillin, which was being released from the military for public use. And he was also pleased that insulin had just come out in a long-acting form, NPH. And he told me that is going to cure diabetes. Just one injection of NPH, once a day and everybody will be cured.

Well, clearly, we know that isn't so and that is kind of why we are here today talking about these things. But his favorite line was, back then -- and this is the Orzeck --- number one, is that Osler said "to know syphilis is to know medicine." If you knew all that syphilis could do neurologically and cardiovascularually, you knew all there had to know about treating people with any medical diseases.

And my dad felt -- and he opined that he thought that diabetes was the new syphilis. If you knew diabetes in the '40's -- if you could keep them alive, if you could do anything to keep those patients going, that is how you would be able to actually have some positive affect on society.

And as far as I knew, that is all we saw. I mean, I didn't know anything about much of anything medically, you know, when I am still a kid, but it stuck in my mind that what I had seen and the diseases that were -- that my dad would talk about was clearly the ravages of diabetes in this very, very impoverished part of the country where, you know, there was very little money for anything. The government wasn't as munificent then as they are now.

But the other part of it is the Orzeck --- number two -- and this is my --- and this speaks to what
Dr. Levitsky said and this speaks to the panelist this morning, that to my knowledge -- and nobody has come up yet with a good answer to refute what I am going to tell you.

To my knowledge, this statement is as true today as it was when I thought it up 20 years ago and that is, the quality of your care, if you have diabetes, is actually totally dependent on how much money you have period. Period.

We heard of strip problems. You know, you have to beg to get four or five strips in Texas. Medicaid will pay for insulin, but up until very recently they didn’t pay for the syringes. Okay, think about that.

The pins that was talked are a much easier means for people to take insulin because you can dial the dose, carry it with you. There are all kinds of positives. The problem is that if you make somebody take a vial and syringe with them elsewhere, to go out, they are not going to take their insulin. They are embarrassed by it. They have a place to go draw it up. They don’t want to go into the bathroom and do it.

But the pins, just dial it, go, and that is the end of it. Is this false economy for Medicaid in Texas at least? Sure it is. Of course it is. And in your state as well.

The other side of the coin as far as diabetes management in Texas is Medicaid will only pay for strips for a certain meter and that meter is their own proprietary brand meter.

So individuals that want a meter can get it. They just have to call their case worker. The case worker has to put the request in and so on. And then they can only use those strips. So if they run out of strips before their next shipment comes, that is it, they are gone. They can’t even buy it if they wanted to buy those strips at some other outlet because they are unavailable.

So I mean, I am sure somewhere they are saving a lot of money, but they are not really doing much in the way of any value.

So I am going to talk a little bit about diabetes and my perception of what was said earlier and I am going to give you a little different overview. And then I am going to talk about the adult aspects of exactly what Dr. Levitsky just talked about a few minutes ago.

Medicare has decided that they want to know if somebody is a type one, which is now what we used to say is juvenile diabetes. That lingo -- that terminology has to leave.

Type two is the type that was already mentioned concerning the fact that it is an insulin deficient rather than a totally insulin absent state. In other words, virtually every person with type two diabetes has more insulin in their system than somebody without diabetes at all. They just can't use it.

And it is that utilization that creates the management problems and why it becomes so insidious over time that higher levels aren't really met with the knowledge base of the patient so they don't do that much about it. And why they are the ones, the type two patients are now fueling the renal dialysis industry and having problems with blindness and definitely with the neuropathy.

Now Medicare has come up with guidelines, which probably should be utilized in some form or another. They say that to be a type one -- because they are the group that used to be called, as you see in your notes, brittle or labile diabetes.

There was nothing brittle or labile about the diabetes of the patients that were called that. It was the brittleness and the lability of the physicians that couldn't come up with a program because the insulin available then was so off the mark that people were taking injections in the morning of what was supposed to be rapid acting insulin regular and some time around 6:30 at night, the insulin was kicking in and they didn't have a clue why they were getting hypoglycemic when they had just eaten maybe an hour before, but the food hadn't really gotten in yet.

So Medicare says you need to have a positive beta cell autoantibody test. What is that? When you are a type one diabetic, as Maureen said, you have a problem with something that is attacking your pancreas destroying the beta cells, the insulin producing cells.

And if you get -- and virtually everybody with type one -- or everybody with type one that has it because of an autoimmune process; not a process where their pancreas was removed; not a process where it was inflamed to where it self-destructed, so-to-speak, but where they actually had it on a natural basis there would be a positive beta cell autoantibody test and that is all you need. If you have that, that is it, it is type one.

If you don't have that, then they look to see what a C-peptide is. Now I am not going to spend -- I have medical students that can't grasp this, but C-peptide is a protein in the blood that is secreted unit for unit pretty much with insulin.

So if you have a lot of C-peptide, you have got a lot of insulin and vice versa. If you don't have a lot of C-peptide, then you are not naturally making insulin. And it is the way that we have discovered an awful lot of factitious diseases out there, by measuring C-peptide.

But if you have C-peptide, Medicare says it can only be 110 percent of the lowest figure for the range. Let's say the range is one to five, it is pretty close, but let's use that for an example, one to five, and if you have a C-peptide that is less than 1.1, then you are a type one by Medicare's definition, and it works. I mean, it is close enough. It takes away all subjectiveness and now you have total objectivity.

It has to have an elevated glucose at the time to show the insulin was stressed and if there is renal failure, the guidelines are different, but that is essentially what it is. That is Medicare's approach to type one.

Now, my other comments concerning diabetes has to do with the -- excuse me for a second, has to do with the fact that the statement in Attachment A, by brittle and labile, we need to get rid of that. We also need to recognize that, as has been mentioned, diabetes in the child is a difficult disease for everybody to contend with. Although it is interesting that in my opinion, in my observations, the younger you have it -- I mean younger, two or three years of age, not just because the child doesn't have any other knowledge base except to take insulin on a regular basis, it just seems to be better tolerated overall, even into the future for complications.

The lack of health insurance or access to quality medical care, that is a major, major, major problem. And has been mentioned, if there is a way to somehow factor in age and parental observations, perhaps we can come up with a positive as far as putting diabetes into the lists that are looked at as far as disability.

Now endocrine diseases in general are a very compact group and there is no endocrine disease -- pure endocrine disease in which the diagnosis of that disease would automatically qualify somebody to be considered for disability; not one. Because all of them, although the current guidelines are woefully out of day, as you know, that is why we are here, all of them can be treated and all of them have the ability to be monitored on a regular basis.

There are 850 pages in the ICD --- book, which is the coding book that ADA puts out that everybody uses. Insurance companies live by it and those of us that are physicians should live by it too. 850 pages in the latest issue. Here are the number of pages, five, that have to deal with every code relating to patients with an endocrine disorder. This is it.

It is a very small compact and very easily dealt with diagnostic approach. But then, of course, we have to deal with what to do as far as therapy. So if you have a primary hypoparathyroid patient and the guidelines are that you need to have a calcium above 11 and an elevated PTH. Why? I mean, you are not going to let -- the patient isn't going to come in saying I am disabled, I have hypoparathyroid. They are going to be treated. It is the effective therapy that has to be looked at when you are looking at what the overall problems may or may not be with the individual.

Now for whatever reason, the adult listings -- this is my section that start with 9 instead of 109, seem to have been written by people from a different planet, on a different galaxy --

(Laughter)

DR. ORZECK: -- than what we see in 109. I mean, nobody went back and actually cross-referenced and said why do we mention pseudo-hypoparathyroidism, which is a very unusual, very interesting disease in which the kidneys don't make enough of a certain enzyme, if you will, to retain calcium. So it is as if the kidneys are just letting calcium flow out of the body. It is not listed in the adult listings, but it is primarily an adult disease.

I also agree that there should be other parameters. They say, for instance, for hypoparathyroidism, generalize the calcification of bone, but there is no way that is quantified.

What about T-scores? We have bone densities now. They are not men. And we are just not looking at what the total, you know, picture is. I have already mentioned pseudo-hypoparathyroidism. I don't have any idea why we have to wait for severe recurrent tetany. I don't think anybody is going to not take their medication and go into tetany.

Tetany is where the muscles contract. You are thinking about a charlie horse when you run or don't run right or walk right. You wait until your entire body is wracked with muscle spasm and if you are a patient, you will lick the grout from the wall in your bathroom to get the calcium if that is what it takes.

There was a question about diabetes insipidus. Okay, diabetes insipidus before 10 or 15 years ago -- I think DDAPP came out maybe 20 years ago, if anybody can tell me. Dr. Levitsky says that probably -- so if you didn't have DDAPP, which is a way to put back in the kidney what is missing so that the urine flow isn't so excessive.

If you do that -- you know, before that, you literally had to drink constantly just to keep the --- up in your body so you wouldn't shrink and get dehydrated within the vascular system. It is not even an issue anymore. In fact, I don't even see why it is listed at all as these diseases are listed, except to be dismissive as with proper therapy, they should not be a problem.

There is -- probably, as was mentioned, one case somewhere in this world have somebody with, what we call, nephrogenic DI -- nephrogenic diabetes insipidus in the kidney that isn't going to respond to the treatment approach. But we showed in 1972 how we can prevent that even before we had DDAPP, we were even, surprisingly enough, using a diuretic. A diuretic fools the kidney into thinking it should do something in some cases and retain the fluid. Obviously, DDAPP came in.

You know, hypofunction of the adrenocortex isn't mentioned in the adult side. That is much more of a problem, which is called addison's disease and is hypofunction.

Diabetes, we have already gone over. And I also agree what used to be a problem with gonadal dysgenesis turner's. These are women who are missing one of their X chromosomes, so they have one X and no other and so they are, what we say, typically female.

They look female, clinically female. They may have some internal genitalia issues, but the point is that now we know what we are looking at. We have given -- these children now get growth hormone. These children get estrogen to go through puberty at the appropriate times. That is not a disability.

None of the endocrine diagnosis that I have mentioned or any that are in this book, as I said earlier, are in and of themselves a means to certify somebody or even consider them as disabled. It is only if after what would be considered appropriate therapy.

For instance, we have -- you know, the patient with pseudo-hypoparathyroidism, because of this calcium leak through their kidney, take 24 to 30 calcium tablets a day. Now that is not quite what we would expect somebody to have to do, but we have nothing else we can do, but it is curative. They don't get into trouble. And if they do, then they take another four to six a day until everything sorts out.

So it is not -- it is a disease, but it is not a disease necessarily that is a determining factor as far as disability.

Thyroid disorders, short of anything relating to the fact that a woman makes hormones or doesn't as part of any disease process, thyroid disease is the most common endocrine problem. In fact, it is probably the most common non-sex related issue and treatment of this country. I think that -- I think I have read that. I don't have proof that I can follow that up with it.

But none of these people, even if they are hypothyroid, they get treated -- if they are hypothyroid they get treated and if they don't follow their treatment program, something bad is going to happen, but that is not a disability per se of the endocrine organ system.

So my dad probably would be very proud if he were here to see what I have been doing in the endocrine world. And I go back to the reservations -- just as an aside, while I have about a minute left, two or three times a year from Texas to work with them, to see patients in the clinic and to see patients that I have befriended over the last 10 to 15 years.

But I got tired and they got tired of me inviting everybody to the reservation -- we would have to drive about 70 miles from Port Angeles to get to the reservation. Well, legally I could then treat them because I was on sovereign land with the tribe's blessing.

So don’t ever try to get a license in another state 30 or more years after you have gotten your license in your primary state, because it is -- they want every minute of every day since you entered medical school.

But I managed to find things and I managed to get enough records and so now I am licensed in Washington, so I can now -- you know, I can now kind of be my dad’s itinerant physician revisited now in 2005 to go up there and kind of run the circuit myself in Western Washington on somewhat better road and definitely a better car.

I still have his saddle bags. I still have them. They are 70 years old and in them are the cylinders, laboriously typed on these labels. He -- you know, I just find these things all the time, including this weekend, I found another one, with four of the things that had no value. Potassium ---, boy, it is purple. Your urine turns purple. You know, I asked him why he did that and he said because they think that it is working. If the urine turns purple, then they must be doing some good.

And I am filling these things. I had no clue. I mean, I thought my God, this man is a genius. He is treating all these people. What a great wish it is. You look at the names on them and you realize that they are nothing, absolutely nothing.

But he did it by sheer dint of his being a physician and laying on of the hands and that is kind of what I am coming here telling you we need to do with this. Thanks.

(Applause)

DR. HETLAND: I would like to thank our speakers. And in particular, I need to -- there are two announcements I need to make. We need to thank Dr. Orzeck very, very much because he found out the end of last week, by his national organization calling him in Houston, that he was going to be presenting here in

Atlanta this week. And so, Monday morning I was emailing him our regulations and questions saying could you please talk on this two days later? Okay.

My other comment has to do with how old our regulations are. I forgot to mention that Dr. Levitsky is the President of the Lawson Wilkins Pediatric Endocrine Society. And Dr. Lawson Wilkins was the preceptor for Dr. Schuster when he was in medical school. So, yes, our regulations are kind of from the last century, if not more.

I need to remind people to identify themselves when they are speaking. Also we have questionnaires that we would like to have you fill out in terms of reviewing how the conference was and giving us feedback.

And I have a note that our conference tomorrow is going to be changing. We are going to be on the first floor rooms in the Woodrow A and B. I think there will be signs. But you don't have to come to the gym tomorrow to find us. Okay. The floor is open for questions.

Audience Questions and Discussion Session

DR. HETLAND: Yes, please.

MS. KLUBERTANZ: Terry Klubertanz, from National Association of Disability Examiners. Did I understand you correctly, Dr. Orzeck, when you were saying that in your opinion there is no need to have any endocrine listings?

DR. ORZECK: No, what I said was there was no need to, in and of themselves, have the listings as an endocrine disease due to whatever reason.

Let me give an example and maybe this will help. If somebody is hypoparathyroid and they don't know it, by the time it is diagnosed, sometimes they are so osteoarthitic, they have fractured and they have developed disability because of it. But the mere fact that somebody has hypoparathydroidism at the outset and it is treated, in and of itself, is not a disabling problem.

I don't want this section to disappear. I just think there has to be more focus on the effects of what is going on, similar to the diabetes comments this morning. In and of itself, diabetes is not disabling, but it can very definitely get out of control and create an awful lot of problems.

MS. KLUBERTANZ: So basically, despite prescribed treatment or despite optimal treatment or whatever?

DR. ORZECK: Exactly.

DT. HETLAND: Okay, you guys, if you don't start talking, I am going to start asking questions.

DR. BUDA: Hi, Frank Buda, from the Regional Office in Atlanta and I also work for LHA and I just have kind of an overall observation because I, fortunately or unfortunately, am able to help adjudicate --

DR. HETLAND: Can you speak a little louder, please?

DR. BUDA: I am fortunately able to help adjudicate multiple specialties, including pediatrics and neurology and some of the others. And so I know we have been focusing on the listings per se and I certainly would agree that many of them are quite antiquated, but in the evaluation process I don't think as many aspects, for example, with diabetes are going unadjudicated.

For example, the individual with the autonomic neuropathy. They often have a positive tilt test and they would be adjudicated under 11.03 as an equal. So that is being addressed -- I mean, even the abdominal angina could be looked at under 11.03 as an equal.

In terms of some of the children with the difficulties with their social interactions, in short having their parent be with them all the time, it is true, I think we need to definitely change the listings. But when we look at this in sequential analysis, we look at finally at various functional domains for children. And certainly, if the child can't go anywhere without a parent being with them, I think that that is a rather extreme impairment in your socialization abilities.

So we, in essence, are looking at these things, but we are looking at them perhaps not specifically under the endocrine listings. And I would certainly agree that this needs to be changed so that it becomes more apparent to everyone that we are really looking at the various aspects, particularly, of diabetes.

DR. LEVITSKY: I appreciate that, but in 20 years in Illinois and 15 years in Massachusetts, I have yet to see a child get approved for SSI based upon the fact that their management was so intense and so clearly, some thought needs to be put into that.

DR. BUDA: Oh, I definitely thinks it needs to be expanded, but there is a mechanism in there. Whether or not it is being utilized effectively I can’t tell you.

DR. LEVITSKY: Then maybe we need to learn to play the game the way it is available to the --- so you don’t have to do that.

DR. BUDA: Well, yes, it is a matter of, you know, where things fit in in terms of the program. I often tell individuals, that I may be training, that my concept of disability, your concept of disability, you need to leave that behind you because it is what the program’s concept of disability is and how things fit into that program.

DR. ORZECK: I agree. I absolutely, totally agree. The disease itself that may have triggered it is not the disabling diagnosis. It is whatever complication -- the way you have diabetes lined out now is perfect.

You have got the neurologic, you have got the retinal, you have got the renal and probably even need to have the cardiac -- you know, cardiovascular. Because the actual causation of the disability is not what that blood sugar is at that point in time. It is what it has been.

DR. BUDA: It is true. And on the adult side they left out -- I think they left the renal out, but we do have a very good set of renal listings and it says renal disease for any reason. And so, if there is a nephropathy secondary diabetes, it would be adjudicated under the 6.00 listings.

But I think in all fairness, there should be a separate listing in the 9.00's that say renal disease, you know, look at the criteria in 6.00.

DR. ORZECK: Good. I would hope that would take place across the board.

DR. BUDA: Yes. And I am -- you know, as I was thinking about all of this I was wondering about somehow in childhood referencing one of the 112.00 listings, maybe 112.02, the mental listings.

Certainly, if the child is very young and they have diabetes, they are going to have a hypoglycemia event. We were looking at some statistics today about the lower IQ’s, organic mental, which is still the same -- I was referring to, it may be that there may need to be a reference to something like that, because these children do get -- if they are very young when they become diabetic, they do have organic mental issues.

DR. LEVITSKY: The problem is the way the regs are written right now -- and this is true for hypoglycemia alone, is they are written so you close the door after everybody has escaped from the barn. You can’t say we are preventing these organic issues by this kind of intensiveness, you have to have the organic issues and that is a problem.

We don’t want to have to have children get brain damage and it is like the repetitive DKA. I know several families where the recurrent DKA was clearly to keep the family going with the SSI. The family was complicit for failing to be SSI.

DR. BUDA: I think that that is a problem because in order to maintain their benefits and to maintain their income, I guess, the child will need to continue to be disabled and somehow that needs to be fixed. I don’t know how we can fix it because we are a disability program. So theoretically, if you are not disabled, you don’t qualify for the program, which, you know, it is a catch-22.

DR. LEVITSKY: Well, your definition -- well, I don’t think you need -- you are sorry and up in the tree. I read your definition of disability and if someone who needs help with activities of life -- sufficient help with activities of living and if that sufficient help is getting eight blood sugar checks a day and multiple insulin injections and help with managing a mechanical device which keeps your sugar normal, that is a fair amount of help and it would seem that it would qualify.

DR. BUDA: Well, you know, I think that might come through in the sequential analysis for a child because the market -- perhaps impairment in health and physical well-being, the market impairment and the socialization because of all the time that is spent, the feeling of social isolation, that type of thing. So some of that can come through in the sequential analysis.

I think that these need to be sharpened up and I think that the program probably bears a responsibility to make it more apparent in our listings and in our regs, that we are looking at all of those.

DR. HETLAND: Dr. Parks?

DR. PARKS: One of the omissions in the endocrine pediatric --- is disorders of puberty. I wonder if you might comment on whether those fit into the category of sometimes inadequately treated and handicapping conditions.

DR.LEVITSKY: I guess you have something in your mind that I may ask you what you mean. I couldn’t imagine the child who became pubertal very early and was not able to be treated because of a disorder like McQuen Albright, whose family felt they needed to pay special attention to them.

But I am having a little trouble conceptualizing that as a handicap severe enough to be worthy of SSI, but you may have an idea.

DR. PARKS: Yes, I think in some conditions the male, the gonadal --- in that male --- has more residual difficulty in the optimum treatment than some of the other endocrine --- deficiencies where it is simply if you can't make it, you can take it.

DR. LEVITSKY: You mean someone who needs to take thousands of testolactone (sic) pills a day and needs supervision for that if that is available?

DR. PARKS: And even so the treatment is not very effective.

DR. LEVITSKY: And why would they need constant parental supervision, because of behaviors? I am not exactly sure what the -- we will discuss this a little later.

DR. PARKS: Sure. I think it has an impact equally as great as many of the other things that our list -- and it looks like we are moving toward two sort of different points of view.

One is for the children, a view that the SSI is a mechanism for improving care in the family that is financially strapped and unable to comply with all of the demands for care and where this is really not a disability prospective. It is supplementary intensification -- it is funding intensification of care in some areas whether or not it actually works that way, where the mother and the adult were truly thinking of an inability -- an interference with gainful employment.

DR. LEVITSKY: That has probably been implicit all along, hasn't it? In childhood as supplemental Social Security income?

DR. HETLAND: It is certainly not explicit.

DR. LEVITSKY: It is hard to use employment criteria in children.

VOICE: (Away from microphone)

DR. LEVITSKY: Yes, yes.

DR. HETLAND: Dr. Becker?

DR. BECKER: I am Dorothy Becker. Well, I actually was wondering about the need for psychosocial support that we talked about earlier on, since some of the disablement of endocrine disorders, more in childhood than adulthood, that it spills over into adulthood would be the need for proper counseling.

And I was thinking more the gender -- I thought you were going to say something about that --- gender identity problems that are very disabling in adulthood. And I just think that that is -- I didn't see that in any of the listings which may interfere substantially in gainful employment from what I read from what some of these people write.

DR. LEVITSKY: The next administration.

DR. ORZECK: If I can comment on that?

(Laughter)

DR. ORZECK: There are many, many subsets in endocrinology because by nature of endocrinology, it doesn't take much in some chromosomes here or a little gene there to cause just woeful disasters that would otherwise not be expected and we can't list everyone of them.

Dr. Levitsky made the comment about patients with hypoparathyroidism, they can't be treated with surgery or radioactive iodine. You know, I haven't seen one. I know they exist, but are we going to write a note about that aspect of it where you would not expect one per 10 years to actually fit.

Unfortunately, there are a lot of patients who are now called the androgen insensitivity syndrome, which then -- which in the past was testicular feminization. These are --- typically women. Women -- very definitely women, but that they actually have testes because it takes the androgen receptor, if you will, in utero to turn you into a male as opposed to a female.

So you can have the XY chromosome, which is what they, so they are gene typically, i.e., they are male chromosomally, but yet, for all the world they look like they are female. When is this diagnosed? When they don't have periods in their teenage years and then the diagnosis is made and then you have an absolute disaster on your hands.

You have someone who was brought up female and is now going to be told that they have male chromosomes in their system, that they will never reproduce, that they have no way that they are ever going to actually be a “complete female.”

I mean, how do you write a regulation for that type of disability? It is major; it is real and it occurs, unfortunately, regularly, as an example.

DR. BECKER: I did have another question. And you raised the C-peptide issues. One that I have a big beef about and I just wondered whether this impacts on any of the discussion today? Because if it does, I think it needs to fleshed out.

DR. HETLAND: I think you were quoting what is the Medicare qualifications? And if you don’t need those, then you don’t have diabetes?

DR. ORZECK: No, it means then you aren’t eligible for certain Medicare funded support, such as a pump -- such as an insulin pump or other Medicare paid-for items. So it is their approach at trying to get some order into this because, previously, if a physician wrote insulin pump, then as we have heard, the $7,000 piece of equipment flowed out of somebody’s store into their hands, whether it was absolutely needed or not.

So Medicare, to try to get a grip on it, came up with these guidelines. I am not telling you that they are all they are. I am not even telling you that they are valid. I personally think that you could have a higher C-peptide and still be far more insulin dependent than somebody with a lesser number.

I am just telling you one of your ilk in the government has come up with this and you all need to decide if you want to embrace it or come up with your own or don’t deal with it.

DR. HETLAND: Dr. Schuster, help me out. I don’t think that we use any of that definition right now in terms of establishing the medical impairment based on the C-peptides.

DR. BECKER: Well, that is good because if you do those definitions need to be changed.

DR. HETLAND: I have a question, Dr. Levitsky, one of your suggestions was that diabetes insipidus or SIADH for children who are not in control of their fluid intake, how old does a child have to be to be in control?

DR. LEVITSKY: It depends. There may be an intellectual deficit or the way they are getting fed may be different. If you have a child who is getting formula feeds, then they are not in control of their fluid intake because in order to get sufficient calories, they have to take a tremendous amount of liquid.

But there are certainly lots of children who, for one reason or another, are not getting oral feedings, so they can’t say no to fluid. They are getting it with a G-tube or a gastrostomy tube. And so those kids can be 10 years old and not be in control and be at risk. So that would be the piece. It is just if they can’t control it -- and they don’t actually have to have an intellectual deficit to not be in control if they have some sort of problem with intake.

If you are in control of your fluid intake and you have a normal thirst mechanism, unless you decide to go out drinking beer and water, like my patients have occasionally done, you are not going to get into trouble if you take DDAPP as long as you drink only for thirst.

DR. HETLAND: How about like a two or a three-year-old?

DR. LEVITSKY: A two or three-year-old may or may not be in control of their own fluid intake. It depends.

DR. HETLAND: So it is really the emotionally developmental level of the child?

DR. LEVITSKY: Yes, and how they are being fed and their thirst mechanism. But if they have a normal thirst mechanism, but they are being fed by a gastrostomy tube, then they have no control over their thirst. Somebody else is doing it for them.

And this unfortunately happens regularly in the hospital. We doctors all know that the worse thing to do is to admit a child with diabetes insipidus to the hospital and have them put on intravenous infusion. They almost regularly get sodiums that are not what we expect or want because of that.

DR. HETLAND: Well, those of you who are adjudicated, how would you feel about having a regulation that said diabetes insipidus is for children who can't control their own fluid intake? Have any takers? It might be a little difficult.

DR. BUDA: Well, first of all, we do for -- only if you are three years or under and you have to get a gastrostomy, isn't that functional equals? So I think we have taken care of that age group. And the rest of it, I guess would just probably, currently fall into functional analysis.

I mean, if you have to have somebody there all the time and the health and physical well-being is dependent upon that person, you are getting a market issue into domains right off the bat. So I think that we have a mechanism, and whether or not there should be something more explicitly written about it, that I think is something we need to do. It is there, but I don't know if everybody is so aware of it or we adjudicate that they are aware of it and know how to use the mechanism. And I think that that may be the issue and my guess is that we bear a responsibility to make that something that is more readily apparent to adjudicators.

DR. ORZECK: It is also a problem in adults and not adults that are trying to do something wrong. If they have either too much of the hormone that retains fluid inappropriately or too little so that they excrete the fluid inappropriately, after a while, you know, quite often they also forget and lose their adaptive mechanisms and get into a fair amount of trouble if they don't have secondary coping skills going for them or actually take some time to figure out what is happening in the way they feel.

So this is probably the one area in which in endocrinology, if we lay diabetes aside, is outside of this discussion of other endocrinopathies. It is the one that is most difficult because treatment, while available, is still very archaic. It is a very difficult way. It is like my dad being thrilled with that NPH coming out because he knew it was going to work better and, you know, it didn't. And we have now different forms of DDAPP, but it doesn't work any better.

DR. HETLAND: Can you walk me through a little bit more about the young diabetic in terms of when can a young diabetic be able to sense that their blood sugar may be low? And also, at what age is a child able to start participating in their care; perhaps, checking their blood sugars, et cetera?

DR. LEVITSKY: Those are the questions that are multi-leveled I suspect and I am sure that there will be two of my colleagues who will wish to respond to them since the studies that have been done suggest on average a child can sense blood sugar at about age five and tell someone.

Some children are remarkable and can do it earlier and some are later at it. If a child has been maintained with rather low blood sugars for a period of time, since the blood sugar is, what we call, a surrogate marker. It is really a way that we look at what the brain sugar is, but it is not the same as the brain sugar. Some children will not sense the low blood sugar just the way some adults won't. And so, they may not be able to respond. That is the several levels.

Then when can children assist with their control? I have sent three-year olds home able to stick their fingers and probably put their finger out for the strip. I have sent seven-year olds home who knew how to work all the equipment better than their parents. Three weeks later, they were playing with another toy. That was not the toy they were playing with and so they were no longer doing any of those things, even though they were quite technically proficient.

So the more important question is, when is a child emotionally ready to take on many of these responsibilities? And that varies quite a bit, but probably ready with some adult supervision at 11, 12, 13. Although they may be doing some of the activities before that, the integration of those activities is unlikely.

And even at 11, or 12, or 13, I know from my own experience and you all may have experienced this too, did you brush your teeth? The answer yes, means I thought about it.

(Laughter)

DR. LEVITSKY: Well, children at the age of 11 or 12 are routinely given a bottle of insulin, which is enough to give them the Claus VanBelieu award should they wish to receive it. And yet, we give them this, you know, 10,000 units of insulin, we give it to them and we put them in charge of it without thinking that they could do a lot of damage and they are still at the developmental stage where, did you take your insulin? Yes, I thought about it. So that is a big question and it really is probably later in adolescence.

DR. HETLAND: Hand me the mike up here, please.

DR. BECKER: The problem -- if you dissect out --- can they do it -- when can they sense --- and when can they respond to it appropriately? And then, when will they be responsible enough to look after their own care are all very variable.

And as we heard this morning from Maureen, who is not here anymore, I think the worse thing that we can do is
--- is place excessive responsibility on these children too early. And put adults responsible to --- young one. And that --- with rebellion. So it is not so much can they do it, that should they be placed in that kind of position? And I would say no. And they need a grown up; they are not grown ups, they are children and they

need to be treated as children.

And these are children who have something that other kids don't have and they need help to deal with it. And I would agree with Lynne, I have got two-year-olds who can tell that their blood sugar is low and some adults can't.

And there are a lot of other things like the --- neuropathy we heard about this morning that is going to determine whether or not they can feel it. And unfortunately, the poorer the control of the diabetes, the easier the people will feel --- those are the control the most likely they are feel their low blood sugars.

So therefore, they have to test regularly and then have the cognitive maturity to know what to do with the results.

DR. HETLAND: Judy, I am going to ask you, do you have the statistics about how many apply and are denied or rejected on an annual basis? I think sometimes that is helpful just to kind of give a little background.

JUDY: (Away from microphone)

DR. HETLAND: You need a micorphone, sorry.

JUDY: Diabetes or endocrine as a whole?

DR. HETLAND: Diabetes first. It will take me a second.

MR. SKLAR: Just one quick comment on the data, Monte, before we even give it out. Unfortunately, we have not gone into ICD9 coding. We would love to do that and that is something we think will --- much better --- information. So more than likely, whatever data we have mixes together all different types of diabetes, including type one, type two and anything else.

DR. ORZECK: Can I interrupt? Who will do the diagnosing? I mean, who will do the ICD9? The physician's records? Or will it be done internally within your group?

MR. SKLAR: At this point, it is an open question. Likely, the adjudicator in conjunction with the in-house physician and Social Security would.

And likely, that information would be drawn from whatever insurance information or medical records were sent over to Social Security.

DR. ORZECK: That is a real art to code write, so you really need to set your standards very high when you get started.

MR. SKLAR: And fortunately for us, there is only one way to go.

DR. ORZECK: Okay.

MR. SKLAR: So what we are about to provide is very rudimentary. This is a disclaimer.

DR. BECKER: Can I ask a question before we get -- this is Dorothy Becker. I get papers put in front of me regularly, especially at the end -- around spring for children going off to college to get help with their college fees. And so I fill out forms for disability to say that these children have a disability and sometimes they actually do get supplementation for college fees and it depends a lot on how I write it. And I just wonder if that goes through this office or is it a different one?

DR. HETLAND: Who is generating the questionnaires?

DR. BECKER: Oh, this is a disability form -- a standard form that is evaluated.

DR. HETLAND: Is it sent out from the State? What we call the DBS? Then that is probably us. I am not sure how to answer that.

MS. BROWN: (Away from microphone)

DR. HETLAND: I think she lost you. The question -- let me see if I can rephrase it, was whether or not that might be for student benefits?

MS. BROWN: (Away from microphone)

DR. LEVITSKY: I must say when you present those data that I probably am at least one of the people responsible for stealing them because when a parent says to me can we apply for SSI? I say don’t bother, this isn’t child birth.

And parents still do it and of course it isn’t covered, no matter what. Because, you know, if the child isn’t having recurrent diabetic ketoacidosis, et cetera. I think a lot of doctors do that.

MR. EIGEN: This is Barry Eigen. First, I should say there are a number of reasons kids around age 18 might apply for disability benefits from us or asking to fill out a disability form.

One very common reason is that the law requires that if you are already receiving SSI as a child, when you are 18 we have to redetermine your eligibility using the adult rules. So that is one reason a person around college age might be asking you for information for Social Security Disability.

Another reason is, under SSI when you are a child, your parents’ income is counted as your own income with certain deductions. We call that deeming of income. And when children turn 18, if they don’t go to college they become adults in their own right and at that point they might qualify under the income and resources levels of the SSI program.

However, if they go to college, we still count their parents’ income to them. We count them as though they are still part of that family.

And then there is the third thing, which we have just talked about, which Nancy Brown just talked about, which is so that your parents can keep getting benefits in some cases, the children can show that they are disabled.

I have to comment about something that Dr. Levitsky said. I would hope that -- I am trying to think of a politic way to say this, but since I am not very good at this either, I will just say it.

DR. LEVITSKY: Go ahead, say it.

MR. EIGEN: Please don’t ever advise somebody not to apply for benefits. You don’t know what we are going to do. It cost nothing to apply and you could be wrong. And they may not be getting benefits --

(Laughter)

DR. LEVITSKY: I won't do it anymore because I have been at this session and I have heard that you are all thinking about that. But I have spent 35 years now, having children who are basically well get turned down for SSI and they have diabetes.

DR. HETLAND: Dr. Becker has a comment.

DR. BECKER: I am one of the people who says try. However, I must tell you that I have spent hours and hours and hours of wasted time and I don't have that any more.

We were talking a little earlier that the commitments that the medical profession has these days and every time I sneeze I have to fill out a form. And so anything one can do to make the rules as transparent as possible, both to the care giver and to the interpreter, and I think you said, would help a heck of a lot. Because I think there are people who are missing out because they can't or doesn't know the terminology to use. Or people who are getting SSI who shouldn't because somebody does know what terminology to use.

DR. HETLAND: You were talking about the thinness and the thickness. If we ask you to just send in the past year's worth of medical records, would that make your life easier or more difficult?

DR. BECKER: Oh, I would love it. However, sometimes these days when we have three seconds to see a patient, the last year's records may not be as complete as you need. And so, sometimes you may need the first one that tells the whole story and the progress.

DR. HETLAND: That is always an option is to send in the medical records that you have. And certainly from my life in terms of being in academics when my residents would bring me these forms to me, I would just say you go zerox your notes because they are much more complete than anything than the questions that are being asked on these forms. But I understand your scenario too of briefness.

DR. SCHUSTER: I am Frank Schuster from the Central Office. I just want to reiterate what Dr. Hetland just finished saying because I think it is very important. And may I address what Dr. Becker was alluding to.

When we request records, we really want the longitudinal in the record as best as possible because that gives us an idea of what is going on rather than a brief dictated summary from the treating physician, who indicates that my patient is disabled because he has so and so, and so and so, wrong with him.

We like to see what the longitudinal is because that gives us a tremendous amount of information. So I think it is important that we keep that in mind, that that is important to us when we make decisions.

DR. HETLAND: As well as any discharge summaries that you may have. All right, Judy, you are on.

JUDY: All right. Tell me again what you wanted, annual totals of the number of claims of children?

DR. HETLAND: Of children and adults for diabetes.

JUDY: Okay, I have figures for the years 2000 -- for 2005, for children, the total claims in 2000 was 2,360; for adults it was 53,192.

DR. HETLAND: These are total claims of people sending in claims?

JUDY: Correct, total initial claims. It doesn't account for any claims that have gone through the field process, just initial claims for first asking -- first time around. For 2001, children -- child claims 2,479 and adults 55,753. In 2002, childhood claims were 2,695 and adult claims were 63,511.

In 2003, the total initial childhood claims were 2,850 and adult claims 68,763. In 2004, the total claims for children 3,004 and adults 70,554.

And 2005 through October, 3,056 claims for children and 71,395 claims for adults.

DR. HETLAND: These were allowances?

JUDY: This is total claims.

VOICE: (Away from microphone)

JUDY: This is diabetes, total number of claims filed on the basis of diabetes.

DR. HETLAND: Can I just pick one of those years and break it down into allowances and denials?

JUDY: Sure. In ‘05, there were a total childhood claims of 3,056 and the total allowances were 224. That is 7.3 percent of those who claimed disability on the basis of diabetes.

For adults in 2005, 71,395 claims and the total allowances at the initial level were 15,067. This represents 21.1 percent of the total applicants.

DR. HETLAND: Okay, I think that gives us a little bit of a background of what we are dealing with. Granted that our statistics are -- they are not great. Does the panel have any questions for us?

DR. BECKER: This is Dorothy Becker. I am thinking of the pediatric allowances now. And is there any way of telling us -- I am surprised there were only 2,000, so I would have expected more. Can you tell us why 93 percent were turned down?

DR. LEVITSKY: The better question is why were seven percent accepted? Were they all the children who also had seizure disorders and asthma? Those are the ones in my clinic that usually get accepted.

JUDY: There is a little bit of breakdown. For 2005, there were 3,056 total claims. That many children applied for disability on the basis of diabetes. And what we have are diabetes mellitus, hypoglycemia, diabetic acidosis, diabetic and other peripheral neuropathy, diabetic retinopathy and peripheral vascular disease associated with diabetes.

And I have the figures for those -- the numbers, but for the reasons I don't have -- we have codes that tell us the basis on which a claim is not allowed and I don't have those. I only have the end numbers.

Of the 3,056 claims in 2005, 2,984 are coded what we call just diabetes mellitus, 40 hypoglycemia, 22 diabetic acidosis, 5 diabetic and other peripheral neuropathy and 5 diabetic retinopathy is the breakout for -- the breakouts in 56 claims.

DR. LEVITSKY: My case rests.

DR. HETLAND: I think you are absolutely correct in that we, as a program, have a tendency to look at a diabetic case and if we don't see -- you know, if they are hospitalized three times a year for hypoglycemia or three times for DKA, then the case is closed. And we are not doing a good enough job of working all the way through and looking at the functional demands of children in relationship to their developmental status.

DR. BECKER: Can I just say something about hypoglycemia?

DR. HETLAND: Sure.

DR. BECKER: And this is adults and children. So if it is looking for hospitalization, which I was trying to get at, we don't hospitalize these patients for almost anything anymore, and especially not for hypoglycemia. So hospitalization for probably whatever is rewritten needs to be taken out of the ---

DR. HETLAND: I think for hypoglycemia, the standard is more hypoglycemia that is severe enough to require physician intervention.

DR. BECKER: We don't even intervene -- the physicians don't even get called anymore because we teach our patients how to handle it. And then they come back and tell us how many times they did it in the last three months.

DR. HETLAND: Dr. Fernhoff?

DR. FERNHOFF: Thank you. I am Paul Fernhoff and I wear two hats and I am going to speak -- the first one is my 30 years as a disability reviewer here --- as a pediatric consultant. And just to remind -- I want to echo Dr. Buda's thoughts that I do think the regs need to be more transparent about the things.

But if I were coming from another planet looking at the regs, you would only see the surface of --- these claims should be adjudicated. The fact is there medical equivalence, there are functional equivalence, there are other domains that a child is requiring that level of care should be looked at. Whether they are or not, I don't know. That is really what I believe the program is to do.

So therefore, the fact that these numbers that we just got are not -- I don't think that is surprising. The fact is a child is allowed if they are disabled. This is not a program -- unfortunately, it should be, but it is not, to prevent disease.

It is a program that says a child has to be disabled to be on. And we can be sitting here talking about cystic fibrosis, asthma, the same things. All of these conditions requiring an incredible amount of time. And we all know, as pediatricians, that if we are able to prevent it, it makes more sense in the long run.

So I think it goes back to -- someone mentioned this morning about the act of congress. The act of congress should be to think about a prevention program; not a disability program. That is number one.

The second part of my role -- I am going to switch hats for a minute, the reviewer to the physician -- I am a medical geneticist and when the medical genetics program here at Emory -- and although we are reviewing endocrine disorders, to my knowledge after 30 years, it is not a separate section on metabolic disorders of children.

We currently screen -- in the country, we will soon be screening all newborns for about 29 different metabolic conditions, although hypothyroidism and congenital adrenohypoglyplasia and those are covered --- listing.

But I --- and we were in programs from --- to --- disease to various types of fatty acid observation disorders, hypoglycemia and I would request -- and I realize this is --- but we also --- because parents come in --- want to apply --- and say well, there is nothing for that.

So I think the program in terms of pediatrics needs to be looking at --- metabolism metabolic disease as another category because they are totally -- they are not at all addressed in current listings.

We have -- for genetics, we have downs syndrome and all other things, but they really -- that is a big void in the current listings at least on the pediatrics side and to some extent on the adults side.

DR. HETLAND: Dr. Schuster?

DR. SCHUSTER: Dr. Schuster. Just to reiterate again how the program functions as it is, right or wrong, the way it has been is the fact that we don’t really allow disability on the basis of risk factors. We allow disability on the basis of what is, is the person really disabled according to our rules, as faulty as they may be, our rules and regulations.

I think the disparity you saw between the child and the adult statistics here indicate that once the child had developed certain retinopathies, neuropathies and things like that --- to a mode of disability.

The adults have already shown that they --- they have --- they have kidney disease, they have eye disease, they have other things that apparently allow them more so than the fact that they are just diabetic.

And so I think that is the way we have always looked at it and, you know, the --- has put something on the table that maybe congress can look at this in a different light and in terms of preventive, risk factors and things like that. But that would be a whole different ball of wax. That is not the way we function now.

So I just wanted to make everybody aware of that. Thank you.

DR. LEVITSKY: If one looks at the functional domains which are required for disability, these children who are being --- intensively with diabetes. They are not able to care for themselves and have problems with their health and physical well-being and they interact with others differently, so it looks like -- just looking at this list, they don't -- they meet three of the criteria. I think you guys just need to start looking at that.

DR. SCHUSTER: Yes. No, I think that is an important fact. That has been said already several times. Yes, there is -- Dr. Buda, Dr. Monte Hetland and Dr. Reed have all said that. No, that is true. I didn't disregard that at all. That is absolutely the way we have got to look at these facts --- thought about rules and regulations.

We have to use them effectively and we are apparently not always using them effectively. Yes, you are absolutely right.

DR. HETLAND: Mr. Eigen?

MR. EIGEN: Barry Eigen here. A couple of things. First, a quick gloss on what Dr. Fernhoff mentioned. I know he knows this. We do in fact list PKU and some other metabolic disorders in a body system we call, for lack of a better term, the multiple body system body system.

And what we basically say is these impairments are disabling to the extent that they cause other problems. For example, mental retardation and so we have a mental retardation listing. And if you happen to have PKU with mental retardation, you would be covered.

Also, as one of the authors of these childhood rules, I also want to echo what Dr. Schuster has said. And to reassure Dr. Levitsky and the other people in this room that if I had to pick one thing that we was the best thing that we learned today and from our previous work, it is that we have to do a better -- that our functional equivalence will --- of the rules with these domains that you just very correctly read out are probably the opening of the door that we need to go through to improve these listings somehow.

I am not exactly sure how that is, but to me, that is the big insight we are getting out of this meeting.

DR. HETLAND: Okay, last comment.

JUDY: I have other figures that might lend a little insight. The 224 allowances that were in ‘95, of that 224, 108 were allowed on the basis of meeting the listing, 38 medically equaling the listing and then 78 on the basis of functional equals. So we haven’t totally glossed over the idea that we used functional equals.

But it is true, it is probably going to be -- take a greater importance in the future, but that is the way it came out for 2005.

DR. HETLAND: Okay, I think it is time to --- up. Our speakers have been up here for a long, long time. Would you like to thank them?

(Applause)

DR. HETLAND: And who has closing comments?
Mr. Sklar? Ms. Jonas?

(Laughter)

Mr. Sklar: At this point, nothing short of brief thanks to all who have participated in today’s session. You have an invitation to join us tomorrow as well where we will continue at least on some of these themes.

And an acknowledgment from all of us at Social Security that we have a lot of work to do. And we may be coming back to talk with many of you or all of you in the future on how to get this right.

But we obviously have a lot of work ahead of us and this has been invaluable in so many different ways. Not only from exposing some of the flaws in the medical criteria themselves, but from a policy level when policy drives unusual conclusions and behaviors. For example, our standard on hospitalization and so forth, we have to go in and take a really hard look at what it is all about. So thanks and hopefully we will see many of you tomorrow.

(Whereupon the meeting was adjourned at 2:43 p.m.)