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CHILDREN WITH DISABILITIES:
A FUTURE OF CHILDREN EVENT

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Overview:

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Panelists:

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P R O C E E D I N G S

MR. HASKINS: Welcome to Brookings. My name is Ron Haskins, I'm a Senior Fellow here, and along with Belle Sawhill, we run the center here called the Center on Children and Families. And I'm also pleased to be joined by my colleague from Princeton, Janet Currie.

As many of you know, I think I recognize many people here, we publish a journal along with Princeton called *Future of Children*, a widely cited journal, and we publish two issues a year, and every time we publish an issue, we have a public event here at Brookings. And they also have a public event at Princeton.

The event at Brookings focuses on policy issues, and the event at Princeton, or somewhere around Princeton, focuses on practice issues. So this is our 15th volume that we have published, our team from Brookings and Princeton, and this is on children with disabilities. And for some of you who have seen it, I think it's a really solid piece of work, a lot of interesting information.

The field is influx, as it has been for many, many years. And I think you can get a very good –- our intent with volumes like this is for someone to pick up, and between two covers, get a view of lots of the issues and lots of the research and so forth. So I think this volume nicely fulfills that, as Janet will show in just a minute.

Now, let me give you a brief overview of the event. As soon as I get through talking, which will be within, you know, 40 minutes or so, Janet is going to give an overview of the volume. Then I will give a few comments about the policy brief that accompanies -— we always publish a policy for the volume that selects one issue that's related to the volume. In this case, we selected children's SSI since that's an extremely important program for kids with disabilities.

Then we'll have a keynote talk by Ken Apfel. Now, Ken Apfel is stuck in a big accident on 50. He called us about 15 minutes ago. But he thinks he'll be here. So we have at least 25 minutes, because we're about 15 and 10 for the overviews, so we think he'll be here. If he's not, we're going to randomly select somebody from the audience to come up and give a keynote speech. I see several possible candidates already. Belle Sawhill just came in. She could give the keynote speech. The only thing is it would be about mobility and opportunity.

Then we have a wonderful panel of people who have a long history of involvement with SSI, either as scholars, or as congressional staffers, or as lobbyists, and I'll introduce the panel when that time comes.

So now I'm going to say something about our two main speakers. First is Janet Currie who is a Henry Putnam Professor of Economics and Public Affairs at Princeton. She's also the Director of the prestigious center there called the Princeton Center for Health and Wellbeing. She also has a huge bio, and you can see her bio in your materials so you can read more about her. I think it's fair to say she's had an exceptionally distinguished scholarly career and now she's moved into I think what will prove to be an equally distinguished career as a leader in the field.

And then our keynote speaker and a long time fixture in Washington policy circles will be Ken Apfel. Ken was for many years the Chief of Staff for Senator Bill Bradley. I want to tell you, just a personal note here, don't mention to Ken I told you this, that years and years ago, I think 26 to be exact, I was interested in working in Senator Bradley's office as fellow, and Ken had the right to make the decision about who did it, and I did not make the cut, and I've never punished him in any way. So when I introduce him today, if you are here, I would find it necessary to say something crummy, but -– so Ken has been around Washington for a very long time.

He was the Senior Advisor to President Clinton, and then he went over from 1997 to 2001, he headed -– he was the Commissioner of the Social Security Administration. And crucially, he was the head of the Social Security Administration when the very important SSI reforms of 1996 were implemented, and it’s mainly what he’s going to talk about in his keynote address. So first Janet, and then I’ll give a summary, and then hopefully Ken will be here, otherwise, someone from the audience. Janet.

MS. CURRIE: Thank you, Ron, for that kind introduction. So I’m just going to give an overview of the volume which was edited with Robert Khan, who’s a pediatrician at the Children’s Hospital in Cincinnati. And we decided to organize the volume not disability by disability, but according to some overall themes, and I’ll try and give you a sense of what those are.

So the first thing that people talk about with respect to disability is what the trends are, which sometimes I think is a little unfortunate because perhaps it takes away from the idea that whatever the trend is, there’s still children with disabilities and they still need to be served.

But in any case, this figure which I put up is from the first chapter of the volume which shows a general upward trend. And it also shows, if you look under the line, several places where the main questionnaire, this is from the National Health Interview Survey, has been revised.

So an important thing to realize is that there is no consistent measure, definition, or data on disability over time. So it’s quite difficult to actually answer the question about what the trend is. People often are very concerned that changes in legislation might change the measured fraction of children with disabilities. So on this figure on top of the line, it also shows several points where important legislation was enacted. And those don’t seem by and large to have had a major impact on these measured trends.

An important takeaway point from the volume is what the composition of children with disabilities is and how it has changed over time. So this figure, also from the first chapter of the volume, is looking at the leading causes of activity limitations, which is one measure of whether people are disabled or not.

You can see that in the late ‘70’s, early ‘80’s, diseases of the respiratory system is the leading thing. So a lot of people think that asthma is one of the main causes, and that would be in there.

In the early ‘90’s, diseases of the respiratory system are still the leading cause. And then more recently, by 2008 – 2009, the composition seems to have changed. So you have speech problems, learning disabilities, ADHD being the three leading causes of activity limitations. So this is a really important change over time. We’re talking, when we’re talking about disabled children, about a somewhat different population now than in the past.

This table makes that even clearer for 2008/2009. You can see that of the children with disabilities, a very large share are presenting with these other problems, new problems. And, for example, asthma is 8.2 percent compared to say 22 percent of kids with ADHD. So that’s I think really important to keep in mind when we’re discussing children with disabilities.

So one takeaway point then is the rising importance of mental, behavioral, or developmental problems relative to all others, and also that there’s a lack of consensus on the fraction of the measured increase that could be due to changes in diagnosis or the rise of these new diagnoses. And the reason why there’s a lack of consensus I think mainly is that there isn’t really good data.

A second theme of the volume is thinking about the cost of disability, and we’re going to focus on one such cost today. But we took a broad view thinking about cost to children themselves, cost to their families, and then also cost to society.

This figure, which is from the chapter by Stabile and Allin looks at pathways for child health to affect adult outcomes. And the idea here is that there’s a lot of pathways, it affects education, it affects adult health, it can be mediated by parental investments or social investments.

And then one of the costs on the family is in terms of maternal labor market activity. That’s where a lot of the research has focused. And there are a lot of costs, particularly to mothers, in terms of things like managing childhood disability, trying to find child care, and so on. So this table, which is also from the Stabile and Allin paper, represents a heroic effort to kind of look at all the data, summarize the research that’s out there, and come up with a cost.

And I think one takeaway point from this table is that there’s a very wide range of estimates, especially for some things, and then you can see there’s question marks on here which indicate that they couldn’t find any good estimate of cost. So there’s a lot of room for debate about cost.

Two points I wanted to make from this, as well, is that in addition to SSI, Medicaid costs and special education costs are particularly high. So this figure from the paper by Peter Szilagyi looks at insurance coverage. And you can see that almost half of the kids with disability are covered by public insurance.

One reason for that is public insurance is often better than private insurance if you have disabilities, because you don’t have to worry so much about co-pays, maximum payments and so on.

This figure from the Loprest and Aron chapter on education looks at the other piece of this, which is the increase in number of kids in special education, a lot of this being driven by the kinds of diagnoses that we were seeing.

A third theme from the volume that's really came out of all of the papers was the fragmentation of services and the burden that's placed on families in terms of care coordination. It's very difficult to get care, and it's usually the family that's the key link in organizing everything.

It's hard to find one figure to illustrate that. But this figure, again, from the Szilagyi chapter, is looking at insurance coverage. And while most of the kids have insurance coverage full year, there are more than 10 percent of these disabled kids that don't have health insurance coverage through the full year. So this is one of the areas where families would have to scramble.

Now, I guess we sort of know where we are, but there's some discussion of where we would like to be in the volume. This figure is from Jim Perrin chapter talking about quality of care and talking about the concept of a medical home. This is sort of an expanded concept of a medical home which I guess represents an ideal, so ideally the care would be accessible, provided in the children's communities. It would be family centered so the family would be recognized as the principal caregiver and the family would be involved in the care. You would have continuous care, not the sort of episodic care that you might get if you have gaps in your health insurance coverage, comprehensive care, and it would also be coordinated, compassionate and culturally effective.

So in addition to the medical home, a few other areas that were highlighted for improvement in the volume, one is to emphasize functioning in the important domains of the child's life. Instead of having a focus on the disability or the physical attributes of that disability, evaluating the quality of care would evaluate how well are you helping the child to function in the domains that are important to that child, and then also a greater focus on prevention.

So in terms of the functioning, this figure, which is from Jim Paren’s chapter, is making the point that in terms of whether your activities are limited or not, it’s not only a matter of whether you have a disease or you have a condition, it’s also what kind of supports you have, what kind of technology is available to help you, and those things together determine whether or not the disability is actually limiting or not.

This figure is kind of making the same point, listing a whole lot of things that you might want to evaluate in terms of functioning. And usually medical care focuses on the physical symptoms, the disease specific symptoms, and any effects of treatment, and ignores all of these other domains actually of functioning. And finally, in terms of prevention, the chapter by Rauch and Lanphear argues that what we really want to do is shift the curve. So this is one example. The idea is that if you are exposed to say air pollution or tobacco smoke, the curve that describes your lung functioning shifts down. And when you’re young, maybe that won’t make such a big difference, but what it will mean is that later in life, you have a chronic obstructive pulmonary disorder in this particular example.

So the idea is that if you could make changes that shifted the entire curve, that would not only reduce the number of disabled people, but it might improve everybody’s quality of life.

So to summarize, we have a rising measured disability, and a really big part of that is the importance of mental health and developmental problems. We see significant cost of disability to individuals, families, and society, and the real fragmentation of services with a burden on the family as a result.

Some of the ideas for improvement that we talk about in the volume are the idea of a medical home, greater emphasis on functioning, and the importance of prevention. So I'll stop there.

(Applause)

MR. HASKINS: Thank you. Thank you to that nice summary. We have copies of the entire journal available outside for anybody who would like to have one. We also have copies of the policy brief. And also, it's available on the Future of Children web site. If you just google Future of Children, I think it comes up right at the top. And you can get any of our publications, any of the 15 volumes that we've published so far.

So let me talk for just a few minutes about our policy brief which will set the stage. We'll have Ken Apfel, but then we're going to have a panel to discuss primarily the issues in the policy brief.

Let me tell you first, SSI for kids, for those of you who have not followed this program, all of SSI requires two things to meet the eligibility. One, you have to be low income and two, you have to be disabled or elderly. So all parts of the program have to meet those criteria.

For kids, the criteria for disability, which has been quite an adventure over the years, and we'll have a lot more to say about it, now is marked and severe. I'll come back to that. There are about 1.2, a little over 1.2 million children in 2010 on SSI, and it cost about $9 billion. That's just the children's portion. There's also an adult portion, I mean an elderly portion and a portion for adults who are disabled.

And there are three issues now that I want to just briefly give you an idea about, because I hope they'll be the substance of the comments by the people on our panel, and I would call those perennial issues. One is kind of faded now, but in a way, it's the most elementary issue, and the issue is why cash. The second issue is the incentives that are inherent in SSI, and the third is how children actually quality for the program.

So let me just say one word about why cash. We have lots of mean test programs. I recently did some calculations. I think we're now between – the federal government and the state is spending about a trillion dollars on means tested programs. And all families on SSI would be qualified for a boat load of other means tested programs, and yet we have a special SSI cash program for kids who are disabled.

And from the beginning of the program, there's –- some people thought we should have spent the money on better treatment, on out of pocket expenses that the families might have, and not necessarily on income supplement. But advocates for the program responded that's not correct, that there are very good reasons to have a cash supplement.

The first one that Janet has already mentioned is the chapter in the volume by Stabile and Allin. And I was amazed at how many studies there are, and as Janet pointed out, the range. But if you do something crazy like average across something like that, you find out that it cost about $1,000 out of pocket for every family that has a disabled child. Of course, the range is great, as I just said. And even more important, someone almost always has to take off work or even quit work in order to provide for the child. It's often extremely time consuming, not just for direct treatment and care for the child, but also because you have to arrange things, and that's often very complicated.

My wife is about to have surgery, and I have learned firsthand in the last three weeks what it's like to try to coordinate hospitals. We have to go to three different hospitals for four different tests. So that's the kind of thing that you face, and it takes someone to do that.

So Stabile and Allin estimate that the average of lost income for moms is $5,150, and again, the range is huge. So there is really a loss. The second thing is, there's quite good research by Susan Parish, who's at Brandeis, and other people, as well, showing that if you match families on income, families with a disabled child have more difficulty with meeting life needs and pain.

They're more likely to get their phones disconnected; they're more likely to get their electricity shut off and so forth. So there is an argument here by advocates that there really is a need for cash, because these families suffer more than other families even when you match on income. SSI incentives, I think this is really the heart of the problem. There are two issues here. I think Mike Wiseman will talk about these on the panel, I hope he does. One of them is that parents, in many cases, have incentive to try to get kids on SSI.

Now, there are a lot of anecdotes about this, so this does happen. There are parents that do everything they can to get their child in SSI. Sometimes they apply more than once. And let's say that a single mother had two children, and one child is covered by TANF, if the mother gets the second child on SSI, she would get $574 a month additional, so that's –- there's a financial incentive to try to do that.

And the second incentive is, if the child is on TANF, the mom will have a work requirement, but if the mom is on SSI, the won't have to face a work requirement, so there's another incentive.

States also have an incentive to try to get people on SSI for a very obvious reason. SSI is 100 percent federal. And TANF, the states have to split. They get a fixed amount of money in a block grant, and when that's gone, it's gone. They also have to have matching payments, but they would maybe rather save that.

Again, there are anecdotes galore. I am not aware of a systematic study of this, but there are a lot of anecdotes, and I think there are states that do try to do this. So the weakness in both of these points is that there's a lot of anecdotes, but the evidence on either one of them being correct is not necessarily very strong.

A second argument is that the admissions, and this is a controversial point, but the admissions requirements for SSI are quite stiff. It is not easy to get on SSI. And this is an argument that the advocates make. Even if the states are motivated and the family is motivated, it's still difficult to get on SSI.

And another argument is that the rejection rate or the approval rate for people applying -– for kids applying for SSI has been stable for about a decade, it has not increased at all, it's about 40 percent. So a majority of the applicants are rejected, and that hasn't changed.

Third issue, how children qualify, and let me –- I can push these buttons. Okay. So here -– I'm going to try to trace along on this. You can see this is the number of kids on SSI, and the other -– the blue one is the ratio of SSI recipients to children in poverty. They're trying to adjust for population and that sort of thing. And since poverty is one of the qualifications, or low income, then it makes sense to express it that way. And as you can see, it rises a little bit less that way.

So now you can see that there was quite a substantial increase in the early days. And I think a lot of people felt that it was, you know, fairly easy to get on SSI. In 1990, there was a Supreme Court case, and we're very fortunate to have Jonathan Stein here, who was one of the –- among the lawyers in the case, and he will have a chance to correct all the numerous mistakes I'm about to make about the case.

But roughly speaking, the Supreme Court said this is unequal compared to adults because there's no functional assessment for adults. If you can't work, there's a concept called substantial gainful activity, and if you -– adult can't meet that, then they're disabled, that's one of the criteria, and there's nothing like that for kids.

And so SSI wisely developed something called a Functional

Assessment. They talk to teachers and parents and so forth and assess the child's ability for daily tasks, for self care, for cognitive development, for school and so forth. And so that was a response to the Supreme Court case.

And as you can see, that had a big impact on the roles. They went up very substantially. And in 1996, the Walter Reform that Ken is going to talk about in a few minutes, the concept was changed, the IFA was basically outlawed, and a new criterion, the one that I mentioned before, of marked and severe was instituted, and that did have an effect of moderating the roles, although they're going up again now, but nothing like they were in the period before 1996. So this is a point that people who want to reform the program often make, that the roles are still increasing, and not only the roles, but spending on the program is increasing also.

And in a recent book, unfortunately Mary Daly, who is in your program, is not here, because she had a family emergency and she canceled yesterday morning, and Mike Wiseman gets some kind of award. I called him yesterday about 4:00 and he agreed to come this morning. So if he even has notes, it's a triumph.

They cite these data from a national survey that shows that there has not been necessarily an increase. From a national survey, the parents reporting on their children, of health conditions that might limit kids. So there seems to be something of a mismatch here according to Mary Daly and her co-author, Rich Burkhauser from Cornell.

So the definition of disability is still a problem, and I think there's some extremely good responses that advocates make. You'll probably hear some of them in a few minutes. And this issue is still very much alive about whether we do have an appropriate way to qualify kids as compared with adults. Much less complaints about adults qualifying for SSI, although even there there is some issue.

So we'll hear more about that in a few minutes. I would point out, though, in a preliminary way, that one of the big --diagnosis which was mentioned by Janet in her summary, is ADHD, and that stopped increasing in 2005, so it probably does not account for the increase in roles recently. Before that, it may have. But there's a good argument that that is due to improvements in medical diagnosis. So maybe there really is more ADHD out there and conditions like that.

And then I would recall to you that we still have this fact that rejections have been high, and they remain high, and they have not decreased over the years. So there you have it. Those are the three main issues in the policy brief.

I discussed three possible forms which we'll get into in a discussion on the panel, a block grant, which you return authority to the states. My assessment of the politics is that that's not exactly a hot item right now, but it's conceptually a possibility, and a good case for it is made in the Burkhauser and Daly volume.

The second is continuing disability reviews, because there's a strong feeling that kids do actually improve, especially if they get treatment, so maybe they shouldn't get SSI anymore, and if we have more continuing disability reviews, then maybe more kids could leave SSI and return to a normal life. And the Government Accountability Office, I'm showing my age here, is that right, Government Accountability Office, new name, a decade ago or something, I keep right up with these things, estimates that these CDR's save a lot of money. So you spend the money on a CDR, for every dollar, you get about a 12.50 return. But it's not clear that most of this money is spent on the children's assessments.

And then finally, I think something that everybody agrees about, and that is that we ought to help the kids on SSI, especially as they get into their teenage years, to develop skills and employment ability so that they would be able to leave SSI as an adult. And some of them might not qualify as adult, so all the more reason that they ought to have the skills.

SSA has recently started a study several years ago, MDRC is doing a study. If you google MDRC and type in new transition demonstration, it will come right up and you can see the results. There's some encouraging news, and I think this is something everybody could agree about, the question is whether we are willing to spend more money on it and whether SSA is willing to expand these kind of services.

So with that, Ken, I've already introduced you once, and Ken is going to tell us about how the Social Security Administration implemented the reforms back in 2006. So, Ken, thank you so much for coming, I appreciate it.

MR. APFEL: Thank you, Ron. Thank you. Two accidents today, I was a little bit late, I'm sorry. When I got a call from Ron to speak on the history on SSI kids, it forced me to dig through some old files, some old memories, and some old emotions. This was a very trying time in many different ways, bringing back the vortex of wealth that reformed the entire welfare reform package, having my own deep interest and concerns about the plight of vulnerable, disabled kids, and then leading efforts at Social Security to strengthen its institutional legitimacy to be fair to these kids. It was quite a time, and it did bring back a lot of emotions, and it does bring back a lot of emotions.

I served at Health and Human Services and OMB during enactment of welfare reform and then became the Commissioner of Social Security during the implementation of the SSI kid's piece. I served after Belle at OMB, Belle Sawhill, and I worked an awful lot with this gentleman up here.

We first met back when he was a AAAS fellow, and had enormous respect then, and by the time welfare reform was done, had much, much greater respect for integrity and for trying to move your ball, even though we disagree on lots of things, to try to move the ball forward given his values and integrity that I think -– I respect you enormously.

And we spent time at the cabinet table when it was Ron and Ken, during the welfare reform debates when it was President Clinton, and it was Newt Gingrich, and it was Bob Dole, and it was Clay Shaw, Dick Gephardt, trying –- and Alice Rivlin, to try to hammer through the issues. So we not only have history, we have some scars together. A little bit of further context on SSI, SSI kids and going back to some of the stuff that Ron talked about. Back in the 1990's, there was a lot of attention on the -– by the new congressional majorities on the social programs, particularly the social programs that were growing rapidly. And I'm going to be focused on the SSI program today. I'm not going to go to any of the other ones.

But two of the largest increases that were taking place in SSI at that time were SSI for legal immigrants and the SSI kids program, and Ron showed that chart on SSI kids. They both became part of welfare reform. They were both centrally involved in the welfare reform discussions. And actually the issue that brought me close to resignation was the elimination of benefits for legal immigrants that I personally found repugnant. And I know there's been some changes in that area, which I think has been good.

But I must say to my friends on the left that the final bill on welfare reform, I did not share that abhorrence about the changes to the SSI kids program. I thought it went too far, but I didn't feel the same kind of level of moral outrage about some changes there because I thought it was important to look at the eligibility given the rapid changes that have been taking place.

That said, prior to Zebley the Social Security Administration was not doing right by these kids. It was not doing right by these kids. And Zebley forced vast improvements I think in forcing the agency to be thinking about this and regulating in this area in a more appropriate way. That said, with Zebley growth rates going from about 300,000 in 1990 to about a million in ’96, it forced a look at the eligibility to look at where we are, where was that curve going. And the curve, I thought, signaled a serious look.

And while the focus on crazy checks at the time were coaching had been widely debunked, the issues about how kids were getting on the role was getting a lot of political attention, and clearly, some attention needed to be placed I think on the SSI kids program.

So, as I said to my friends on the left, I didn’t cheer the moral outrage, but I’ve got to say to my friends on the right that the House’s initial changes didn’t fit my definition of reform at all, which was to move the program away from the cash entitlement to a block grant, to devolve the program to the states, which I would view as morally reprehensible, frankly, as the SSI kids –- the SSI adults for immigrants changes, which were basically eliminating benefits for vast numbers of people. I would have found that to be clearly as problematic for kids.

The impact of the block grant on those kids I think would have been devastating. And I know that we debate the added costs that are associated with these kids for their families, but I don’t think that tells the whole story. My first graduate degree was in rehabilitation. And I work with individuals with mental impairments and their families, and those families are under great stresses on so many levels, and some of this comes true with the -– comes out with the document that you have before you and some of the points that Ron made during his presentation.

The need for financial stability for these families I think is major. The need for them to have that financial stability that SSI provides to provide an anchor in a very stormy world I think is a centrally important part that I would be deeply concerned about seeing go away.

The SSI -– more history, the SSI kid's block grant was strongly opposed by the Clinton Administration and discredited in the Senate, as well. Instead, the evolution was towards eligibility changes, and there were a few different –- I'm not going to go through all the different line and verse of the different debates that went on during that time, but in enacting those changes, there were restricted eligibility changes that ended up being enacted, a congressional mandate for the Social Security Administration to review, develop regulations, review all the cases within a year, setting in place a very rapid period of time for the Social Security Administration to implement and to start reviewing cases during that time. About 100,000 kids all did lose eligibility during that time.

Frankly, I thought the eligibility changes were more than I thought were called for. But I was at OMB, the law is the law, and from my perch at OMB, I would help to shepherd a fair process forward.

That's when I got nominated to become the Commissioner of Social Security. And my perspective changed a bit when I was asked to serve as the Commissioner, not only to shepherd a process, but having full legal and full authority to both lead and to direct the changes that were going to be taking place.

I went to the United States Senate for my confirmation hearing, Commissioner of Social Security, gigantic management challenges. There weren't a lot of questions about management challenges, giant solvency issues that remain to this day. There actually weren't that many questions about solvency.

A lot of my confirmation hearing was devoted to the SSI kids program, because at this point in time, some kids were coming off the roles, being terminated, and the drum beat of crazy checks kind of gave way to stories of vulnerable kids being thrown under the bus, not easy.

At my confirmation hearing, I committed publicly to a top to bottom review of the process that we were going through at Social Security, and it dominated my first six months, maybe even my first year as Commissioner of Social Security. We discovered a series of problems. Some of it had to do with defining mental impairments, the way that the coding was being done. We concluded that the quality of the case processing needed to be strengthened. We did re-reviews. We reopened the appeals process.

We did a cessation study and concluded that a majority of the kids taken off the roles were not with MR but did have learning problems. We spent, in a word, a lot of time in the agency on trying to strengthen the adjudication process, efforts that continue, I'm pleased to say, under the past two commissioners, to try to find ways to make this adjudication process go forward.

So during that time, we basically turned parts of our agency inside out to try to find a way to make this system work fairly. And in the process, it's very clear that we turned the lives of some of these families inside out, as well.

Fair process, my sense has been that for the past decade and a half, I've viewed the program model and the adjudication system on pretty solid ground. It is very hard to assess disabling conditions with severely disabled kids, and that's always going to be a tough challenge no matter what that process is going to be. When the changes were done, the Social Security Administration projected there would be still be about a -- by 2000, a million kids would be on the roles. So it was not coming down, it was maybe a little bit down, but then coming up just a bit. And we have seen some growth in recent years, at least in part it's pretty clear because of the economy deteriorating, and I'm sure we'll talk about this a little bit more on the upcoming panel. I would hope that a social safety net would have a feature of economic stability, as well.

There are observations after that period of time of trying to find a way to provide a consensus. And during hearing testimony over the course of that year, I think the left and the right was pretty comfortable with where we had come down through that process in terms of doing that adjudication.

A couple of observations for the end here. If a program kicks up in times of economic distress, that's not surprising. Let's definitely, as Ron has pointed out, strengthen the continuing disability reviews to look at these kids over time so that we're making sure the kids who are on the role stay on the roles who are supposed to be on the roles.

Two, and if needed, through research, let's look at the adjudication process; try to find ways to continue to strengthen it. It is hard; it is really hard to do, do fairly and appropriately. So not on crazy checks, but on good research, looking at where -– what are the implications for these kids who are coming on the right –- on the role. So are the right kids coming on? I would say that by and large, it seems to me that there is, but let's continue to do research and look at those kids.

If we look at just one particular challenge and an observation, it's a situation of that 18 year old kid on the SSI roles. His or her peers, without disabling conditions in 2012, is having a heck of a time right now, particularly those who aren't going on to college. This is – they're facing major challenges right now getting their economic footing. These kids are facing even larger challenges in terms of getting their economic footing. So I want to reiterate what Ron had said about the importance of thinking hard about that transition at age 18.

And I guess lastly I'd also say that I think the block grant approach would be a disaster for these families. And I also think it's pretty much of a non-starter in 2013 as it was in 1995.

Conclusion, final conclusion, there’s a lot of young people in the room, you’ve probably never heard of the show, Hill Street Blues. It’s a TV show that was about law enforcement. And to the older people in the room, it was a TV show about local police force trying to provide security for urban populations, urban settings. And the precinct sergeant every morning would meet with his cops before they went out on their beats. And Sergeant Esterhaus was his name, and he would look at the end just before going out, and the very last thing he would say every day, let’s be careful out there, let’s be careful out there.

During (inaudible) at Social Security, we were trying to find a way to get it right and to be careful with those kids. The reality is these are very vulnerable kids, young people living in very vulnerable families. It’s always appropriate to reexamine. It’s always appropriate to look and determine how do we move forward, but let’s be careful out there. Thank you.

(Applause)

MR. HASKINS: One second, we’re going to switch. Please don’t leave the room.

(Pause)

MR. HASKINS: Okay. I have always intended when we have this little break here to try to imitate Joan Rivers and say talk amongst yourselves, talk amongst yourselves, but you did anyway. All right. So now this is usually the most interesting part of the program, not one speaking boring everybody to death, but folks mixing it up a little bit, people with different views. We’re fortunate Ken has been able to stay. He previously had a Board meeting, but the time has changed, so he’s able to stay. And he doesn’t have a microphone, so that’s called a compromise at Brookings, you can stay, but you don’t get a microphone. All right. So Mike Wiseman, the gentleman who agreed last night to come and do this, so I can hardly wait to hear your remarks, Mike.

He's a Research Professor of Public Policy at George Washington University. And as you can tell, he doesn't look a bit like Mary Daly. I want to repeat again, she had a medical emergency and yesterday, unfortunately, had to cancel. So, Mike, thank you very much for filling in for her. Although in the future, I'm always going to wonder about your judgment.

MR. WISEMAN: I expected a price.

MR. HASKINS: Well, that's true, yes. And then Jonathan Stein, who is on Mike's right, I'm not sure that that's an appropriate place for John to be, but that's where he is. He's an attorney at the Philadelphia Community Legal Services, where he's now General Council. He used to run the whole thing. And he's one of the best known advocates in the country for children, I don't think there's any question about that.

He was co-counsel in the Zebley that Ken and I both talked about. And I have heard recently that the Obama Administration would like to hire him as Solicitor General so he could argue their cases.

And then Matt Weidinger, who is on everybody's right, that's appropriate. He's the Staff Director of the Human Resources Subcommittee, on the Ways and Means Committee. He was intimately involved in many, many pieces of important legislation, including the one that Ken condemned a few minutes ago, the Walter Reform law. And now that I think about it, Matt was really the lead staff on the SSI provisions, both the block grant and the reforms that we did manage to get through.

And then finally, Marty Ford, who's an attorney and a long time lobbyist in Washington, very familiar to people who know anything about disability programs, and she's played a leadership role in several organizations in the past and currently. She's now the Director of Public Policy for the ARC of the United States.

Each panelist gets eight minutes to make an opening statement. And recalling that this is Washington and everybody here is friendly, and, you know, try to be as bipartisan as possible. So take it away, eight minutes, and we're going to begin with Mike.

MR. WISEMAN: Well, as you heard, I was drafted, but I'm sort of sitting in for Mary Daly, and if you know Mary, you know that there's a dimensionality issue there. But I do encourage you to look at the Daly/Burkhauser book. But I'm going to question some of their conclusions here. I think the authors and editors of this *Future of Children*, children with disabilities volume need to be credited for a great piece of work, as is the prolific Doctor Haskins here. It's important to understand that the volume goes far beyond the issue of SSI and adds to our sort of sense of the empirical base for concern about where we're going nationally on policy for support for families with children with disabilities.

I found the work depressing a bit because it presents just one more facet of social policy that needs, it seems to me, and probably won't get, at least in the near future, creative governance, but that may be just because I was in a negative frame of mind.

The best I could tell from the memo, I made two contributions, and I want to talk just a bit about those. First is, about three weeks ago when the stuff was in draft, I get this panic call from Ron, which it seems to be the only kind of call I ever get from Ron.

He had a whole set of estimates of the incidents of poverty among children with disabilities and a large collection that said that the rate was on the order of 50 percent and one underlier that said that the rate was 30 percent, and he said where does this come from, are you crazy.

And actually it came from work done at Social Security in which we merged data from the

CPS, the source of most national poverty estimates with administrative data on receipt.

And we discovered that, in fact, many SSI recipient families fail to report SSI or confuse it with social security, and when you add that income into the reports, the official poverty rate goes down. It's still very, very –- it's still high, but remember: the standards for SSI creates some leeway above that, it's low income, not poverty.

But the critical thing there, and it comes out in this volume, is that the standard does not make any adjustment for need. There's no variation on –- the poverty standard has a resources side and it has a need side, and the need side are substantial, and the contribution here is to try to hone in on what that might be, as much as the key estimate in the volume is $6,000 on top of other income.

If you added that, recomputed the poverty standard, I'd be back in the right league. So I want to -– don't read that and make dark marks on it.

The second contribution, it cites, is an estimate that I made in this paper and cited in the back of the memo of the gain from moving a child or an adult from TANF to SSI, and it cites an average of $574 a month nation-wide for –- and a family with a single parent and two children, moving one of the children from SSI the gain over what you have from TANF alone. That dollar figure actually doesn't include the food stamp adjustment, but that's not very important.

I think the important thing about that is that that's an average estimate across all states, and in some states it's much larger, and especially in a state like Texas, where if you can get that child onto SSI, you experience a 268 percent gain in family income over what you have if you don't have it. So it's variation across states in the way the program operates and its interaction with TANF, which is pretty critical.

What I think is important about this is not to emphasize the incentives. These are families trying to take care of themselves and so forth. But to go back, there's more than anecdotal evidence of states pushing -– taking -– responding to the block grant, recognizing that the big gain in cash –- of free cash, freeing up state money from moving children and adults from TANF into SSI and devoting attention to that.

But in a world in which the real benefits for TANF are going down and restrictions at the front door are growing, SSI becomes the only game in town for many families. But while SSI is very good at writing checks, it doesn't do case work, and it doesn't partner well I think, in my experience, with the social services agencies that states are contracting anyway. One of the themes in this volume is fragmentation and I think this process adds to that.

Now, my comment is -– I've got three minutes, but let me say something about additional work that we're doing that's pertinent to this discussion. I have a research assistant, Erica Harbatkin, who was not able to make it on her late night call here this morning, but we've been looking –- all of the numbers you've seen are national aggregates. But there's extraordinary variation across states in the prevalence of SSI receipt, and interestingly in the composition of the qualifying disabilities that get people onto the SSI roles across states.

And the upshot is that the odds of a successful application, of getting an award, and especially if you're a marginal case in the mysterious childhood adolescent disorders not elsewhere classified category are much higher in some states than others.

So I think that a missing element of this is interstate variation. And, of course, part of the problem is that while we have estimates of the prevalence of child disability that are adequate on a national basis, those don't disaggregate to the states.

I couldn't agree more with Ken's argument that we need to worry –- have second and third thoughts about block grants. Mary and Rich, in their volume, talk about the success of TANF as somehow something to look at when thinking about where we should go with SSI policy.

I think that people that talk about success in TANF are typically people who know nothing about TANF, and they're certainly people that have not looked at the record of states in the presence as they responded to the incentive generated by a block grant. More thought needs to be given. Okay. In conclusion, it seems to me the SSI program –- children program, and I say this in the paper that Ron cites, really makes little sense.

There's no variation across the character of disabilities. It makes no sense, given the nature of children disabilities, to make the qualifying standard a monthly income standard. What are we doing talking about the same benefit for children that we have for adults 18 to 65, 64, or the elderly? Surely, the needs, the requirements, the whole operation must be considered differently, and the time has come to think that way.

But if there's a problem with children with disabilities, it's the absence of a vision I think of what could be better, a vision that hangs not just on the word more, we need more of this thing, but what -– suppose that you started again, broke up SSI into three parts, thought about what supplemental security income and services might best be for families with disabilities, what would it look – what would such a program look like?

Now, recognizing that we can't go there, at least it would be helpful to have that and get away from thinking that the best that we can do is incremental reform. Talking a little bit about continuing disability reviews, that raises a whole issue –- a set of issues about what happens when a family is facing the prospect of review and loss of benefit at this vulnerable state, or also talking about the transition from 18 and beyond.

I agree that that's critical and the behavioral consequences for children and their families at age 17 are clearly substantial, but it's not the only gain, and we actually need to start thinking about what we're doing and the plans, the programs, the social support systems for families with these children well before age 17.

Let me close by returning to the vision thing. SSI is a great organization. I like the money. They care. We've seen caring people from -– and I'm about to retire –- throughout the agency, but it is in the character of the agency, and, indeed, it's legislative mandate that they can't do the vision thing.

They can think on the margin, they can think about different approaches to budgeting and the like, but something entirely different is not in their remit, and indeed, they would be challenged were they to do so. So I think the challenge to us is to find the alternative vision and then think about the increments that not necessarily make what we've got marginally better, but what move us from where we are to that vision.

MR. HASKINS: Thank you. Jonathan Stein.

MR. STEIN: Well, thank you to Brookings, Princeton, and to Ron for this opportunity to take part in today's discussion about SSI benefits for children with severe disabilities. I have some written remarks, so if you'll permit me to look down a bit this morning.

My name is Jonathan Stein, I'm General Counsel at Community Legal Services in Philadelphia. Today's issue of the future of children adds a great deal to what is known about children with disabilities. Many of the articles bear directly on our nation's social policies, making clear that children with disabilities, especially in low income families, need more help, not less.

As Janet Currie and Robert Khan put in their excellent introduction, low income children with disabilities are in double jeopardy. Special attention must be paid to ensure they have a meaningful chance at a full, productive, independent, and rewarding life.

As I will discuss in greater detail, the SSI program provides critical support for low income children with severe disabilities and should be preserved in its current structure. It increases economic security for children with disabilities, and in combination with Medicaid, helps families meet their disabled children's basic and special needs.

However, there are a number of reforms which I will also discuss that would strengthen the program and make it even more effective. As recently as the 1960's, children with disabilities were stigmatized. Parents were expected to put children with impairments into institutions. And it was in President Nixon's signing of the SSI program in 1972 that marked a critical point in the expansion of services and supports for individuals with disabilities.

In the 40 years since, the income support from SSI and a network of supports and services has enabled millions of disabled children to remain at home with their families and in their communities. As the Ways and Means Committee said in 1971, "Disabled children in low income households are among the most disadvantaged of all Americans and are deserving of special assistance in order to help them become self-supporting members of our society."

That rationale holds true today, and indeed, it's only growing stronger. There is far greater expectation today that children with disabilities will be cared for at home rather than in institutions. But raising a child with severe disabilities presents a considerable financial and emotional burden especially for low income families who need and deserve extra help to provide for their children's basic and special needs.

In the more than 40 years of advocating for disabled children and their families, I have seen firsthand the considerable hardship faced by low income families with disabled children. Likewise, I have seen the difference that SSI can make. Just a few weeks ago, I represented a young child with autism. He and his mother had been homeless. And she was unable to even buy him a $20 tape recorder to help him learn to speak.

The extra expenses incurred and the income lost when a parent reduces his or her hours or leaves a job all together to stay home to care for a child with severe disability can be crushing. Special needs, flare ups, and emergencies such as asthma attacks or behavioral episodes in school can happen at any time, especially for parents whose jobs provide little flexibility or sick time, one too many afternoons leaving early for a child's doctor appointments, or when the school calls to say the child must be taken home or to the hospital can mean the loss of a job.

In their excellent *Future of Children* article, Stabile and Allin find that between 10 and 30 percent of parents with disabled children report stopped working entirely. And between 15 and 68 percent report cutting back work hours to care for their children with disabilities. Maintaining work while caring for a disabled child is especially hard for single parents. Stabile and Allin also document an array of extra expenses accrued by families raising children with disabilities. Many expenses are not covered by Medicaid and private insurance, forcing families to shoulder the costs out of pocket. Susan Parish at the Lower Institute on Disability Policy at Brandeis University documents that families with a disabled child are twice as likely as other families with children to experience material hardships, even controlling for income, education, and other similar factors.

These hardships can include food insecurity such as skipping meals and running out of food and housing and utility hardships such as doubling up to avoid homelessness or utility service shut-offs.

Professor Parish also found that families raising more than one disabled child are even harder hit. Over 70 percent of families with more than one disabled child receiving SSI experience such material hardships even with income support from SSI.

Also documented by Stabile and Allin, raising a child with disabilities can take a considerable toll on parental health, further contributing to depressed parental employment and earnings. Divorce and separation are considerably more likely among couples with children with disabilities, leading to family dissolution.

Much has been made of the increase in child enrollment over time. Yes, the number of children receiving SSI has increased with about 1.3 million disabled children receiving SSI at present. But considered in the broader context of rising childhood poverty, population growth, and increased prevalence in child with disability, it makes sense that more children would be receiving SSI. Child poverty has sky rocketed in recent years, with more than 16 million or one in five children living in poverty today. Since SSI is a means tested program, more children means more children eligible for SSI. More poor children means there will be more children eligible for SSI.

But the share of poor and low income children receiving SSI has remained constant for over a decade, with seven to eight percent of poor children and three to four percent of low income children receiving SSI. And the program's overall award rate has remained stable at about 39 percent for over a decade.

Providing the support for children with disabilities need to reach their potential and have the greatest chance of achieving self-sufficiency must be one of our foremost priorities for the benefit of the children themselves, as well as for our nation.

Findings in the *Future of Children* articles, and there are a number, by Stabile and Allin, by Rauch and Lanphear and Delaney and Smith, call for investing in children now, because those investments will pay off later through reduced disability and health care spending, increased human capital, and a stronger economy. A multitude of research finds that whether children's needs were met in the younger years is the biggest factor in outcomes in later life. Boosting a poor child's annual family income by just a few thousand dollars has been associated with increased school achievement, graduation rates, employment capacity, and earning potential as an adult. By helping families meet the children's basic and special needs, SSI gives youth with disabilities a better chance at a successful life as adults.

And in my concluding part of my remarks, I should say that contrary to the assumption in Ron's policy brief, advocates for disabled children are not against reforming SSI. What we oppose is changing the program in ways that would be harmful to children and families, and those are the families and children who SSI were meant to support, such as cutting benefits or converting it into some kind of block grant.

Instead, advocates support a number of reforms to strengthen SSI and make it more effective. Since my time is very short here, just a few ideas. One, strengthen work incentives. While the children's SSI program does include robust work incentives for teens and young adults, they should be strengthened to enable youth with disabilities to access internships and other early work experiences that prepare them for adult employment.

For instance, a student earned income exclusion could be expanded as recommended by David Wittenberg and Pamela Loprest to enable SSI youth to try work with no risk to their benefits. This reform could result in long term program savings with successful and supporting SSI youth with disabilities transitioning to work.

The second: improving coordination of services and supports. In their *Future of Children* article, Aron and Loprest point out that services for youth with disabilities are commonly offered in isolation even work at cross purposes. Transition aged youth can find themselves shut out from VOC ED programs due to minimum age requirements and limited space.

Government agency corroboration and coordination is needed particularly for youth in transition.

We've mentioned, at least Ron has mentioned the time CDR's. CDR's have a very important role. They're an efficient and cost saving mechanism in the program. Additional funding for CDR's are, of course, needed for SSA to do its job in this area.

A fourth idea is indexing the assets limitation to inflation and increasing that assets test. The SSI assets limits test has not been increased since 1989. And today is just $2,000 for an individual and $3,000 for a couple, a parent and child. Adjusted for inflation, that would be over $10,000 today. This incredibly low asset limit forces families to remain in poverty and prevents them from having virtually any savings in cases of emergencies, schooling needs, or even needed home repairs. The SSI assets test should be increased and then indexed to inflation. Okay. And the last two reforms are set out in a handout out there are to address families who are in foreclosed homes, where they lose SSI because that foreclosed home they may no longer be living in is considered a resource.

There are children of parents who are employed who suddenly become cut off from SSI because the unemployment income is viewed differently than the earned income that the family had been earning, or the father had been earning, or mother had been earning before.

So there are a number of forums we're urging, including Outreach. This is still a program that many families do not know about, and there's a role for government in informing the public about this program, as well.

In conclusion, as an essential support for low income children with disabilities, we believe that SSI must be preserved in its current structure and strengthened to help our nation’s most vulnerable children and youth achieve their potential and becoming contributing members of society. Thank you for this opportunity to speak this morning.

MR. HASKINS: Thank you.

(Applause)

MR. HASKINS: Matt, I regret to inform you that Jonathan took a minute and a half of your time, so –-

MR. WEIDINGER: Okay.

MR. HASKINS: That’s called equity.

MR. WEIDINGER: Redistribution of time. All right, thank you.

MR. HASKINS: I was going to block grant you two more minutes.

MR. WEIDINGER: Excellent, outstanding. Well, welcome, thank you for inviting me, Ron, I appreciate it. For those who don’t know, I occupy what is informally known as the Ron Haskins Memorial Chair at the Ways and Means Committee. I’m the staff director for –-

MR. HASKINS: I’m still alive.

MR. WEIDINGER: Near memorial, I’m sorry. That’s the subcommittee that has jurisdiction over the SSI program under the auspice of the Ways and Means Committee. I’m obliged to say that my comments are not for attribution, nor to be confused with the views of the members of the Committee. So, Ron, no matter how much you want, you can’t say that Congressman Levin was speaking here today, or Mr. McDermott.

What I’m going to do is talk about recent activity on the Hill, especially in my subcommittee. I’m going to talk about some specific issues in the policy brief as I see them and then talk about prospects for future reform, sort of along the lines of Michael

Wiseman's vision thing that he described.

The most recent sort of key event on the Hill was a hearing that the subcommittee held last October, at which both Jonathan and Richard Berkhouser testified on sort of a review of children's issues.

Some of that was sort of kicked off by an article or a series of articles that appeared in the *Boston Globe* that referred to SSI as the other welfare. Concern expressed in that article reviewed things like a rising share of kids with mental impairments, questions about whether parents were actually encouraged to place their kids on psychotropic meds so that they would improve their chances of qualifying.

That led to a bipartisan group of members, including Chairman Davis, the Subcommittee Chairman I work for, asking GAO basically to take a look at that. GAO testified at that hearing and released some basically preliminary findings. The final report is in the offing. We expect that probably later this spring.

You know, basically what was reviewed at that hearing was a lot of the charts and graphs that you have seen today, so a rising number of kids, rising prevalence of mental impairments, concerns about ADHD, members having questions about that. From a subcommittee and sort of an educational standpoint on the Hill, a large part of activities like that really get at making sure members understand and have kind of the basis of knowledge to make reasonable decisions about a program like this, which is highly complicated. We have many new members on the subcommittee. Chairman Davis is a new member of the subcommittee, actually a retiring member of the subcommittee, so that challenge continues. So that's something I know you all work with and deal with and participate in, but that's going to be sort of an ongoing theme going forward.

Some of the things the members questioned were, we have a large body of members, a lot of freshman republican and sort of junior republicans, and I think a lot of democrats, too, that ask some serious questions about outcomes of programs, like what can we establish, what do we know results from a program like this that, you know, has been cited and spends about $9 billion just in cash as aside benefits per year.

And there the track record kind of gets a little bit murky, because, you know, once you sort of get past the, well, the program provides monthly checks and those are good for various reasons that have been cited, the next question is, well, how much does the program contribute to somebody going to work, how much does the program promote individuals finishing say their high school degrees.

There it gets a little bit harder to make an argument that the program as it's currently designed is the optimal program that somebody would want to design. For example, 30 percent of all kids at 17 or 18 and 45 percent of those due to mental or behavioral impairments have dropped out of high school. Well, you know, you wouldn't wish that for your own kid. Should a program like this tolerate that and continue providing checks in those circumstances?

What are some other concerns? So Ron made the point, and I think Ken talked a little bit about this, about incentives, and Michael talked about it, too, about incentives both for kids to come on and concerns about that and kids to remain on state incentives, and in that, there is, you know, sort of a packet of background on that that people have commented on.

One thing that we noted in preparing numbers for the hearing is 61 percent of child SSI recipients lived in a household where there was no parental earned income in that year. That, in effect, makes the disabled kid the bread winner for the family. So you can understand, you know, sort of echoing Jonathan's point about how essential the program is in those circumstances. A question is should anything be done about that? What should Congress think and policy-makers think about incentives like that and how that plays out through the course of the program?

So as one congressional hearing and one subcommittee, I would say, in a program where there hasn't been a whole lot of legislative activity in recent years suggests, this is not a soup to nuts review of the SSI program that is poised to have major programmatic changes I would say in the near future.

But, as I'll talk in a second, there are major pressures on this program because there's major pressures on all federal programs. So you can ask yourself, what kind of reforms might someone consider, what sort of things have been talked about in the background, not so much in public.

There have been discussion about sliding scale benefits. I think Jonathan sort of made illusions about sort of situations where there are multiple kids in the same household. Someone might look at this program and say, should there be time limits on total receipt of lifetime benefits, for example, once kids get into school and parents may have more time that they can devote to work, should there be some step up expectation as there was in welfare reform on sort of the TANF side.

Several people have talked about increased CDR's, so making sure that the right kids are on the right role -– on the roles at the right time. Mandatory determination, is there any reason why the program makes -– requires reviews at age 18, but doesn't require reviews of kids when they start school, start high school, hit puberty, some other level. So there are a bunch of things that sort of go from that. And as several have commented and several have expressed serious concern about, there's always the block grant and let states sort of figure out what to make of the social program as they have been sort of expected to make of other social programs.

In terms of what I would view the near future as holding, at least in terms of congressional activity, I think maybe the most likely area of interest is the issue of high school completion for kids and sort of promoting more high school graduation for older kids on SSI.

Funding for CDR’s I think, you know, refer to that. There’s bipartisan concern on that. But beyond that, what’s the future going to hold for the program?

I would argue that, so far at least, the SSI has been shielded from some of the types of scrutiny that other programs have started to receive for budgetary and other reasons, and I think there’s a number of reasons why that is.

First, a lot of effective advocacy from Jonathan and folks making their arguments about what is now a mostly federal program. So it’s logical to come to Washington, make your argument, convince the federal policy-makers to maintain the program as it is, or make an argument for expanding it, and so far that has helped. We’ve got obviously a very compelling group of recipients, disabled kids and kids with families dealing with those issues.

Additionally, it’s a very large, very complicated program. So for the same reason that you have a multi chapter volume that gets into all sorts of issues that cover SSI, but extend well beyond SSI, that makes it very hard for policy-makers, I would say, to develop the expertise to effect programmatic changes.

There was a small group of members in the ‘90’s who were instrumental in getting reforms done back then. I would imagine in the future you’ll have a similar small group of members because it’s a highly complicated program that involves a whole lot of issues that take a long time to develop expertise in.

But if you ask yourself, how will programs receive scrutiny going forward and how does SSI fit into that, so in an era of trillion dollar deficits, what’s to become of this program, first of all, I would think that SSI is more vulnerable to activity, to changes going forward than it has been in the past.

First of all, it spends a whole lot. The kids program is $9 billion; the overall program is $50 billion. That's a half a trillion dollars over 10 years. That's a large target, I would say, from a budgetary standpoint. It has a limited partnership; it's mostly a federally funded program. Evidence, in some cases, is of outcomes that members regard as positive is questionable.

There's been concern about fraud and abuse in the program, as Ron talked about checks. Other programs have focused more on services or tax credits or things like that that some members like to call tax cuts to pay for with federal general revenues, not payroll taxes that are dedicated. You want to think about sort of the unemployment insurance extended benefits debate. The argument there was those benefits were paid for by individuals going forward. You can make an argument about that, but that certainly strengthens an argument for keeping a program as it is.

And finally, there's questions about whether social services in general can or should shift more towards the states. So I would argue that there's a whole bunch of reasons to think that the folks in this room will play an instrumental role in developing further reforms to the SSI program, and you really need to, because there will be pressure to make reform of the SSI program going forward.

And I think some members left to their own devices might look at that with a sort of blunter lens than some of you all will. And I would encourage you to really focus on the program and come up with prudent reforms, because I don't view the future of the SSI program, especially with all the pressures on both Congress and the committee going forward as one where it's going to be, oh well, we will make a strong argument for expanding the program, for adding benefits to the program, to increasing spending on the program. I think the pressure will head in the opposite direction, and it would be very prudent for folks that want to preserve an effective SSI program, and I count our members in that group to have solid policy arguments and solid policy reforms to develop. So thank you.

MR. HASKINS: Thank you, Matt. Marty Ford.

MS. FORD: Great, thank you, Ron. And I thank Brookings and Princeton for having me here today to participate in this discussion. SSI benefits are critical in providing children with a stable, secure home environment and the opportunity for integration into community life, including the world of work as adults.

Families experience many additional costs in raising their children with severe disabilities in the family home and avoiding institutionalization. We know from our experience with children, and it was documented in the journal on the *Future of Children*, that there are indirect costs associated with the impact of the child’s needs on parental employment. The parents themselves must forego often job opportunities and advancements to accommodate the needs of their children with severe disabilities.

These opportunity costs resulting in lost income can include quitting a job to care for a child, for instance, when children are younger, or when their needs require constant intervention at school, at daycare, or doctor visits, working fewer hours to meet a child’s needs to allow the parent to be home when the child is at home, for instance, for children who can never be left alone regardless of age, turning down a better job because the hours, demands, and responsibilities are incompatible with their child’s needs, changing work hours or changing jobs, losing a job because of care giving demand, job lock, being unable to move on to a better job because of the need to protect health insurance, for instance, location lock, being unable to move to another city or state where they would have to set up a whole new array of services, doctors, home modifications, school system accommodations, daycare, where there’s no room for error in the balance to support their child in daily life, or to avoid starting over in a whole new state where the Medicaid home and community based services waiting list may be years long, and some of you know this well from your own work.

This loss of job mobility results in reduced economic opportunity for the entire family, not just the parents and the child with the disability. All of these opportunity costs have an impact on everyone, including other siblings, as do the SSI program resource limits which have significant impact on the parent’s ability to plan for their other children, college educations, home emergencies, et cetera.

In addition to meeting the basic needs of food, clothing, and shelter through the replacement of that lost parental income, the benefits are also intended to meet the unique needs of the child with disabilities. Families report spending the cash benefit from those items and support that they are otherwise unable to afford or unable to receive through health care providers or others like the school system.

They also purchase disability related items that go over and above the typical costs of childhood. These things include diapers and other incontinent supplies that can cost hundreds of dollars a month for an older, larger child. You have to use adult diapers for a child who’s 16 – 17 years old and uses extra large. That’s very expensive.

Specialized foods for medical diets, transportation, including an accessible van, wheelchairs, and adaptive equipment such as communication devices and things that have to be changed as the child grows, adaptive and educational toys, medications, specialized child care for a child who can never be left alone regardless of age, for example, a 15 year old who must be met at the bus every day and cannot be left alone when they return home.

Housing modifications and repairs, medical bills not covered by insurance, specialized services and therapy such as speech, physical and occupational therapies that go beyond coverage limits. If there's more than one child with disabilities in the family, they will need to spend more. These costs are magnified, they are not shared costs. In short, these are very severely disabled children whose families have low income and low resources or they wouldn't qualify for this program. They receive very modest cash benefits from SSI, and these cash benefits pay for supports that are not easily replicated as services from some other program. I believe the program is operating as intended.

These issues are not limited to families of children on SSI. The (inaudible) conducted a nation-wide survey in 2010 called the Fine Survey, not limited to SSI eligibility. Nearly 5,000 family caregivers responded and reported unmet needs in many areas. And this was not just minor children, this is children and adults.

But 82 percent of caregivers reported having problems in overall economic security, and nearly half reported having more care giving responsibilities than they could comfortably handle. This is a general problem for families.

A word I think is important here about the decrease in allowances based on intellectual disability formerly known as mental retardation, although we do not use that term anymore, and the increase in the proportion of other mental impairments such as ADHD, and the question about whether there are any logical reasons for what appears to be a C change in the prevalence of intellectual disability for these children. Professionals in the field indicate that they are seeing pretty much exactly the same children, but the diagnoses have changed. It's clear that compared to 30 years ago, the following has occurred: an increased use of genome tests with resulting increased diagnostic precision, labeling, and intervention that result in children receiving a named disorder based on biology rather than the more general intellectual disability diagnosis.

So you’re not seeing a difference in disability, you’re seeing a difference in diagnosis and labeling.

An increased precision in diagnosis of specific syndromes by more detailed descriptions of the child’s actual functioning and the development and use of more precise psychological testing.

An increased use of less stigmatizing labels by people afraid of being sued, such as schools and diagnosticians, and an increase in things like learning disability, and a decrease in terms like mental retardation.

An increased involvement by parents in the diagnosis who keep looking for a name and a reason for their child’s impairment and who won’t accept a vague conclusory pronouncement about their child’s global disability, they want something more precise. And the expansion of certain diagnoses such as from autism to the broader autism spectrum disorder also affects this area. Also, you have to keep in mind: we’re talking about social security and social security’s data systems. SSA reports the primary diagnosis. You may still have intellectual disability present, but it may not be listed as the primary diagnosis, and when you have something more precise that is also in their child’s record.

So I think we have to be more careful about what we’re saying in terms of whether or not there is a decline in intellectual disability and an increase in other mental disorders. You may not be seeing a change at all, but simply a change in what is being recorded or how it is being viewed.

In terms of recommendations, yes, we believe that improvements to the children’s SSI program can be made, and, in fact, agree with recommendations along the –- suggested by Ron. We believe that in terms of continuing disability reviews, we support adequate funding for SSA to conduct timely reviews, and we support strengthening SSI's work incentives for older youth and young adults to allow them to gain earlier and better work experiences and to understand those work incentives that do exist.

We oppose a block grant for this program. And as Jonathan suggested, we would also suggest an increase in the asset limits and having them adjusted annually for inflation, in fact, bringing them up to what they would be had they been adjusted for inflation since the inflexion of the program, and an increase in the income disregards and having those adjusted annually and bringing them up to what they would have been had the program –- had they been adjusted annually since inception of the program.

To those last two being designed to help bring families out of poverty. It's time that we stop insisting that families have two to 3,000 in the bank. That's actually quite irresponsible of our nation to put families in that position, to have virtually nothing in the bank for other children, for their children with severe disabilities, and for family emergencies. Thank you.

MR. HASKINS: Thank you.

(Applause)

MR. HASKINS: So I want to talk seriously about the issue of incentives here. First of all, conceptually, there's no doubt that there are incentives for parents and for states that get as many kids on SSI as they can, I mean just conceptually, okay.

And then along come things like the article in the *Boston Globe* that I had not heard before prompted to hearing, but for those of you who read the thing in the *Boston Globe*, it's quite impressive, and there were witnesses at the hearing and went into, you know, lots of anecdotes and so forth.

And Mike says there is evidence that the states actually systematically try to put kids on SSI. So is anybody here worried about the incentives? I mean -– and do you have ideas about what to do about the incentives?

MR. STEIN: And the basic answer is really a so what answer in terms –- and can be refined in the following way. The amount of money –- the average grant is $592 a month. So we're not talking about a very large grant. In fact, one-third of all children on SSI are in poverty. So this is not the most generous of benefits.

But, you know, the question really asks the question of, you know, why do we have this program. I mean the, you know, there is a basis to have a program that meets children's basic needs and special needs. The arguments have been set forward, and Congress has repeatedly I think reinforced those policies that this program is basically needed as an income support program.

And studies have shown that parents still have incentive to work. There is a high percentage of parents of kids with SSI who are in the work force. And I think too much can be made of this very narrow, almost insanely narrow economic analysis of incentives being –- some evil or great problem here when it really isn't.

MR. HASKINS: So, Mike, insanely economic issue of we shouldn't worry about these incentives, and you say that the states do not only worry about them, but take advantage of them.

MR. WISEMAN: No, I think we have a program with eligibility standards people who are eligible should get. And I think it would be inappropriate for states not to assist families in attempting to obtain benefits for which they are eligible.

What was alarming about the series in the *Boston Globe* was the notion that it was prevalent within the population eligible, but the strategy for getting –- qualifying a child for SSI was to make sure that their doctor prescribed the psychotropic medicine. As long as they were on drugs, that was prima fascia evidence that they were eligible, and moreover, to continue eligibility, so that if CDR time came up, by golly, the fact that my child is still taking this pill every morning, that was evidence that the disability was still there.

So the notion that –- it's almost the same way that the problem with –- for adults with SSI, which is that we spend so much time driving home that you must convince people that you're not capable of substantial, gainful activity to get into this program, you work hard at that month after month convincing you're not, and then you cross the line, and we say welcome to SSI, here's your ticket to work. You have worked on a mindset that says that it's not possible, and then you think you can turn it around, you think that that has no consequences. So I think that the incentive issue is there. And the other side of it, as well, is that it seems to be not so much that it's bad to be assisting families in need, as these families are, but when you see it, it seems to be a substitute for thinking more about the kind of support for families in general that TANF was supposed to provide.

So it's a manifestation not really of concern about the wellbeing of these potentially eligible families, per se, but rather a manifestation for excessive focus in that direction as opposed to general support for families.

So the bottom line is that you need to think about what we want to happen with these children, what we want to happen with these families, who it is that's thinking about what the circumstances are that lead to coordination of benefits and the like, and the incentives for states to do that seem to be missing. The incentives seem to focus everything on the game of finding -– of hiring consultants and so forth to get people through that SSA door.

MR. HASKINS: Ken, go ahead. John can wait. Go ahead, Ken.

MR. APFEL: I want each and every person in the room to picture themselves as a pretty low income family. I'd like each and every person in the room to put themselves in place of a -– the head of a household with someone with major disabling conditions.

MR. HASKINS: That's much worse, we can hear you.

MR. APFEL: Particularly if you're a single parent family. You have a severely disabled child. Is that an incentive to get that person on the SSI program? Duh. It seems to me that what it is, it's a –- this is your child, you have a -– I would have a moral imperative to say I want to help this kid, here's a way that I can provide some support for this kid. Is that an incentive? I would say yes. Is it a moral imperative? It's your disabled child, I would say yes. So I would equate moral imperative and incentive.

MR. STEIN: And I would just like to say, you know, I'm really surprised that someone –- a respected academic would give credence to a very superficial, erroneous *Boston Globe* newspaper article to -– we've taken a very close scrutiny of that series. This woman journalist knew very little about the social security system, had no clue that medications were not the ticket to get SSI.

In fact, the Social Security Administration did a study directly as a result of that and found that medications did not, you know, was not the determinate factor of getting SSI particularly for the ADHD group that she seemed to be so obsessed about.

And I just think, you know, the GAO, when they did their study, said they did not give weight to the *Boston Globe* series, they were going to do their own research, which they're undertaking, and the fact that preliminary findings seem to suggest that the hearing that Matt talked about about medications which was the whole linchpin of her *Globe* series was not, you know, the factor or the basis for benefits.

MR. HASKINS: Okay. I want to move on.

MR. STEIN: So I hope you have some –- give some caution in your future remarks about relying on that series.

MR. HASKINS: I hope you listen more carefully when you hear other people talk.

MR. STEIN: I was clarifying what the issue –- that had been raised by that article. I wasn't saying I subscribe to it.

MR. HASKINS: Matt, do you want to add anything?

MR. WEIDINGER: Yeah. The only thing I would add to that is you can be concerned about individuals thinking that they understand how the SSI program and its incentives work without that necessarily being how the program actually works. So the word in the street is, oh, put your kid on psychotropic meds and get them onto the SSI program, that's a concern whether or not that actually results in the child getting onto the SSI program.

So I would be concerned as a policy-maker or somebody, you know, concerned about families that the word on the street is, place your kid on meds, and doctors are telling people, and people think that that's the way the program works, and you improve their chances of getting a check.

MR. STEIN: If that were true, yes.

MR. HASKINS: Okay. Let's go on to another issue. I think Matt issued a legitimate challenge, not just about this program, but for advocates and for people who think we should spend money on children and any other in social need. But we are going to cut, we are going to cut programs over the next two, three, five, 10 years. We don't have any choice; we're going to do it.

So if SSI's number comes up, and the Ways and Means Committee decides to make some reforms and they're going to save some money, have you got any ideas? Have you got anything to offer up that will save money, Jonathan?

MR. STEIN: Well, we did suggest the CDR process as one that needs more funding, that will save money, it's a very cost effective, you know, program, one dollar in for CDR saves you $10 down the line, but we don't want the kinds of savings where families and children are hurt.

And what I find surprising from my friend Matt's presentation to you about what's going on on the Hill is no mention of the fact that the House republican budget resolution has called for a $3 and a half billion cut in SSI children's disabilities benefits. There's about 150,000 children, 10 percent of children in families where there's more than one disabled child who would have a precipitous loss of income, children who would fall off the cliff in terms of their benefit levels. Yet there was not one witness at the hearing last October that even considered this or urged this, not one member, both republican and democrat, on that committee that brought this up, yet we have, out of the blue, this provision that will clearly hurt children in large families, no empirical evidence of economies of scale.

Do two children use one wheelchair, is that the idea? And another evidence that shows in 70 percent of families with more than one disabled child, there is extreme hardship due to lack of income or reduced income.

So, you know, there are changes that will help children and families, and there are changes, including the one being proposed right now that's on the table on the Hill that will seriously hurt children. And there's a big difference between –-

MR. HASKINS: Marty, do you want to end? Jonathan -–

MR. STEIN: -- those two kinds of changes.

MR. HASKINS: -- there are five people on this panel. Try to make your answer shorter, and you don't have to answer everything.

MR. STEIN: Excuse me?

MR. HASKINS: I say there are five people on the panel. I see the five. Go ahead.

MS. FORD: I would just say I agree with Jonathan about the CDR's, that should be being done in all of the programs on a regular basis. Too often it's been up and down based on whether the funding has been available, and it should be consistent and adequate over time. The work incentive should be there, and we're pushing constantly for better work incentives in the program.

I would suggest that the Ways and Means Committee should also be looking at revenues. The budget issues in our nation cannot be dealt with solely by cuts in programs to people who need them. The issues must be balanced, and it's got to be a balance of cuts and revenues, and it cannot be just more cuts.

MR. HASKINS: Matt, you need to take the message back to the Ways and Means Committee that a Brookings audience wants more revenues.

MR. WEIDINGER: Thank you.

MR. HASKINS: Ken.

MR. STEIN: Well, I would just add that I'm not sure they need to. Is Belle Sawhill still here?

MR. HASKINS: She's got her jacket on, though, she's on her way out the door, you better hurry.

MR. STEIN: I was in OMB. You have to be pragmatic, there's no doubt, and so part of the challenge that we're going to have is how we're going to resolve the next couple of years in this whole fiscal state. So I think that it's legitimate to raise what Matt raised. I would think that Simpson-Bowls tended to exempt most of the low income programs or almost all the low income programs from looking as a major focus for deficit reduction.

MR. WEIDINGER: Not housing, I don't think.

MR. STEIN: And that would be something that would be more in line with my personal values. But I also think that, if you're pragmatic in this town, you're thinking about, okay, what are we going to do here, how are we going to work compromise, what's it going to be. So I don't have anything to offer up, and I wouldn't even if I did, which I don't, but I think it's incumbent on all of us to be thinking about if we are going to move towards a pragmatic whatever, and if the Simpson-Bowls framework doesn't hold, that low income programs are going to be a part of a compromise, and it's going to take some rethinking.

MR. HASKINS: I think it is clear, Matt, forgive me for saying this, but I don't think we're going to get serious bipartisan agreement to cuts in these kind of programs, that is means tested programs, without additional revenues. I mean it's just in the nature of Washington. To the audience for questions. Not comments, try to keep them short. Belle, were you dying to say something a minute ago?

MS. SAWHILL: I would like to say something.

MR. HASKINS: Give the microphone to that woman.

MS. SAWHILL: I'll talk loud for the moment. I don't have my coat on because I wanted to disappear because I think this has been a fascinating discussion and a wonderful volume, and congratulations to Janet and everybody on the panel, and wonderful to have you here, Ken.

But I was thinking, when people clapped in favor of more revenues, and I'm thinking poor Matt, he's got a tough job here, that there are many spending programs that aren't means tested. And, in fact, the overwhelming number of dollars, as most of you know, in the federal budget are not for these means tested programs; they're for the non-means tested programs. They go to people like me, people with gray hair.

And so I guess my question, especially to some of the advocates here, and those of you who are on the more progressive side of the spectrum, yes, we need revenues, but are we also willing to see some retrenchment in the big non-means tested health and income support programs? And, Ken, I've going to refer that question to you initially.

MR. APFEL: Can I answer?

MR. HASKINS: Go ahead.

MR. APFEL: I've been very vocal on the need for, as part of a compromise, looking at the social insurance framework and making it more progressive, and that would mean seeing reductions in the middle top in terms of long term benefit promises as part of a long term framework. What makes me kind of nervous about saying that is -–

MR. HASKINS: Have you discussed this with Nancy Pelosi lately --

MR. APFEL: I've not, but I've been out there on this, and the reality is, I think if -– just as I said before, we have to be thinking about different alternatives. I think we have to be thinking about the different alternatives here. That said, my biggest concern is that framework that says let's take social insurance program and means test them, let's take means tested programs and block grant, let's take block grant programs and terminate them, I don't like that.

MR. HASKINS: Somebody else in the audience.

SPEAKER: Hi. Thanks very much. I'm very interested, particularly, Matt, in terms of your request for outcome indicators. I'm wondering whether anyone has really looked at the public sector cost associated with the 60 percent of applicants who are not eligible for the SSI children's program.

We know that there's a large number of youth in juvenile detention now who have mental health issues, and I just wonder if anyone has looked at what happens in the absence of economic assistance, and how those applicants, again, begin to put a claim on other types of public sector costs, and whether investments in this type of program would prevent expenses in other sectors down the road.

MR. WEIDINGER: I'm sure there are studies on that. Janet or Ron.

MR. HASKINS: I'm not aware of any. It's a great idea for a study.

MR. WEIDINGER: I mean the answer is some are going to be on TANF, some are going to be on food stamps, some will receive UI for a time. I mean there are other programs that will step in.

MR. HASKINS: There were a lot or problems and you couldn't have random assignments, so there are limitations, but, you know, it would be a very interesting study. And I would not begin with the assumption the kids in the control group, the ones who got the benefit, would necessarily be better off. I just think it would be a very good study to do. It would help. Go ahead, yeah.

MS. CURRIE: So this is one of the really big problems in doing research on these programs, is there is no data in this country that follows kids from birth to some outcome. We don't collect that kind of data. And then every time there's a discussion of these programs, people then say: well, where's the evidence? It's not like there isn't any evidence because we know the program doesn't work, there isn't any evidence because it's impossible to even do the study given the lack of data infrastructure.

SPEAKER: (Off mic)

MS. CURRIE: Maybe actually. I was on the Advisory Board for the National Children's Study for a while. It's being reconceived as far as I know. It seems to be kind of narrowly focused on medical things, so it would be good for this particular question. I think one of the issues with the National Children's Study is, will the data ever really be made available to a wide range of researchers, or will it be like a typical medical study where only a few people have access to it to look at some specific questions, and I think that's a really important issue with respect to the National Children's Study.

MR. HASKINS: Another question from the audience. Well, we are going to play stump the panel. We played stump the audience today, how about that.

MR. WEIDINGER: Can I make a pitch?

MR. HASKINS: Yeah.

MR. WEIDINGER: On the point about data, for a bill that Congressman Berg and Congressman Doggett have introduced of our subcommittee that would open up the National Directory of New Hires, which you're familiar with, to researchers to evaluate employment and training programs. So, you know, at least from a standpoint of work and earnings, there may be more data on the way that can attest to some of these programs, to answer your question.

MR. HASKINS: Yes, one more question, on your left.

SPEAKER: This is a follow up on the data actually. It's a little bit dated, but there were two waves of longitudinal data on kids coming out of special education. I guess, Marty, you probably remember this, in the '90's, right. But I don't think the situation has changed. And with kids with disabilities who have a mental impairment, there are extraordinarily high dropout rates across all income groups and extraordinarily high arrest rates two years out of school.

So I think we're doing very badly by that group of kids, and I think before we go ahead and do something around graduation rates, Matt, we need to be careful to think about what's happening to all kids with those kinds of problems and their functional difficulties and how we get all those kids to do better before we can punish the SSI kids.

MR. HASKINS: So, Matt, here's a serious question. We could go on like this for another 10 minutes and think of all kinds of spectacular studies. Do you think there's any chance that the Ways and Means Committee would give SSA some money to actually collect data on these issues?

MR. WEIDINGER: Possibly. Let me make one more point on CDR's. There's agreement on CDR's, and I think everybody correctly notes that CDR's, if more were done, would result in savings. I blame Ken actually, because there's this OMB directive that says that CDO can't score those savings, because you can't score –- CDO doesn't score -– yeah, discretionary spending as resulting in entitlement savings. So while we all agree that would be a great thing, that isn't going to cut it if the committee actually has to sit down and decide.

MR. APFEL: Well, let's ask Jack Smalligan then who's the OMB person. Jack can change anything.

MR. HASKINS: We actually want to hear what you have to say.

SPEAKER: Matt is right that we don't actually score for (inaudible) purposes. The savings –-

MR. HASKINS: But is there a solution? Congress can do anything it wants. Why couldn't they declare its entitlement?

SPEAKER: And if you did declare -– also score an IRS audit for the revenue it gets from the audit. I mean there's a convention going back to 1990 that we don't actually score for (inaudible) purposes changes in level of effort. But, yeah, Congress could change its mind, but it isn't just an old rule. The irony, as Ken would know, is that we actually had special rules from 1996 to 2002 to provide support –- dedicated funding for CDR's. I mean once the appropriations and the appropriators funded CDR during that period.

MR. HASKINS: Did CDR –-

SPEAKER: And that was during my time.

SPEAKER: And they reflected it in their baseline. So it generated deficit reduction in the baseline.

MR. HASKINS: Okay. So let's get Ken to go back. Would you be willing to serve in the Romney Administration? All right. One more question.

MS. VANDAN: Hello. I'm Janet Vandan, Social Security Administration, Childhood Disability Policy. Mr. Apfel, greetings, Marty, and Jonathan. I'm someone that works in the weeds, so all of this discussion about money and the financial outcomes goes beyond what I ever deal with. I'm a regulation and rule writer, I worked on the Zebley regs and on all of the final regs. I wanted to mention, with respect to –-

MR. HASKINS: You need to get to a question, okay?

MS. VANDAN: Yeah. Within the program, we have had some generation of ideas such as CDR starting at age six, changing the name of the program; get the word disability out of it to move towards something that's about enablement rather than disability. Mr. Wiseman had a comment that I didn't follow up clearly. You said divide the SSI program into three parts. Do you recall saying that? I didn't understand.

MR. WISEMAN: It's what you're talking about, that after all, what's called for a person 65 and older, that's a much different issue than what you call -– so the point is that we (inaudible) For Children is a separate program, and you think of it that way, and then at that point, you might think about disconnecting the benefit levels, as well, although I realize that that can put things at risk that people don't want put at risk. But functionally, it doesn't make sense to have this common structure in that way.

And I'd like just to add that I think that this discussion of CDR's is a little glib here. First of all, the savings are predicted not, as I understand it, on the basis of an analysis of CDR's for children, it's CDR's for –- again, it's a much different situation to try to transfer predicted savings from one to the other.

And the other thing about CDR's is this continuing disability review. And I think that the reason why we see people willing to say, yeah, more money for CDR's, because these disabilities continue. The review is the talk about what's happening in terms of addressing the disability, our efforts being made to accommodate and the like. But that's a different perspective on what reviewing case action is about than just is the original diagnosis, does it still apply, and in many of these children, it certainly does, that's not the issue, it's how –-

MR. HASKINS: Well, now we see the real cynical Mike Wiseman. The one issue we all agree on, and Mike has got to take a shot at it. So I think we'll end this program on that note. Thank you very much for coming and we look forward to seeing you again.

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