U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

FRIDAY, MARCH 14, 2008

The Committee met in the Rotunda Room, 8th Floor, the Ronald Reagan Building, Washington, DC at 9:00 a.m., Thomas Insel, Chair, presiding.

PRESENT:

THOMAS R. INSEL, M.D., IACC Chair, National Institute of Mental Health

ANN WAGNER, Ph.D., IACC Executive Secretary, National Institute of Mental Health

DUANE F. ALEXANDER, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

JAMES F. BATTEY, M.D., Ph.D., National Institute on Deafness and Other Communication Disorders

ELLEN W. BLACKWELL, M.S.W., Centers for Medicare and Medicaid Services

JEFF BUCK, Ph.D., Substance Abuse and Mental Health Services Administration (For Dr. Larke Huang)

PETER VAN DYCK, M.D., M.P.H., Health Resources and Services Administration

MARGARET GIANNINI, M.D., F.A.A.P., Office of Disability, U.S. Department of Health and Human Services

LEE GROSSMAN, Autism Society of America

PRESENT (continued):

GAILE R. HOULE, Ph.D., U.S. Department of Education

YVETTE M. JANVIER, M.D., Children’s Specialized Hospital

STORY LANDIS, Ph.D., National Institute of Neurological Disorders and Stroke

CINDY LAWLER, Ph.D., National Institute of Environmental Health Sciences

CHRISTINE McKEE, J.D.

PATRICIA A. MORRISSEY, Ph.D., Administration for Children and Families

LYN REDWOOD, R.N., M.S.N., Coalition for SafeMinds

CATHERINE RICE, Ph.D., National Center on Birth Defects and Developmental Disabilities (For Dr. Edwin Trevathan)

STEPHEN M.SHORE, Ed.D., Autism Spectrum Consulting

ALISON TEPPER SINGER, M.B.A., Autism Speaks

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PROCEEDINGS

[9:00 a.m.]

DR. INSEL: Welcome to everyone to the second Interagency Autism Coordinating Committee meeting. It is nearly the Ides of March. It has been since November 30th when we had our first meeting, and a lot has happened in the interim. December was, of course, a huge month for autism genetics, with several major findings in the course of about three to four weeks in December.

The month of January was a time when we saw a lot of research advances with the CADDRE sites moving into the field from CDC. I think many of you know that two of the big multi-site pharmacology efforts through the NIH ended up their work and are now in the data analysis period, with hopes of pulling all that together.

Of course, these last couple of weeks have been rather extraordinary for autism with all the news about the Hannah Poling case and the interest, in the media especially, but the public generally about trying to understand this little girl's case of autism and its relationship to vaccines and other events.

So it has been a busy few months. A lot is happening. Among the many things that have been happening have been the work on the strategic plan, which we will come back to in a little while.

We are going to use most of today's meeting really for two things. One is to revisit a discussion that we had at the first meeting about the role of services and the IACC. We want to look at that first. Then, after we have had that discussion, we are going to really enter into a much deeper conversation about the nature of the strategic plan and to think about where we are going with this and how you think we should move forward to get from where we are to where we need to be.

We will have a presentation that will take you up to this point in terms of what has been done and then some discussion about ways that we can go forward.

Before we start any of that, since we are still getting to know each other a bit, I thought it would be worth doing another round of introductions. So, maybe, Stephen, if you will start. Just say who you are and, if you represent someone, who you represent. We will just go quickly around the room that way. Thanks.

DR. SHORE: Stephen Shore. I just recently finished my doctoral dissertation on comparative approaches for treating children on the autism spectrum, with the goal of matching best practice to the needs of children with autism.

My relation to autism; I am my own autistic child. I'm a board member of the ASA, National Chapter, and I travel around the world helping children with autism lead fulfilling and productive lives.

Lee, you're on.

MR. GROSSMAN: Thank you, Stephen. I can't follow that. I'm Lee Grossman. I'm president and CEO of the Autism Society of America. Most importantly, I am the father of a 20-year-old young man with autism.

DR. BATTEY: I'm Jim Battey. I have been at NIH for 25 years. I'm currently the director of the National Institute on Deafness and Other Communication Disorders.

DR. McKEE: I'm Christine McKee. I don't have any organizational affiliations. I'm a mother of an eight-year-old girl with autism.

DR. GIANNINI: I'm Peg Giannini. I'm the director of the Office on Disabilities for Secretary Leavitt and President Bush.

DR. BUCK: I'm Jeff Buck. I'm here representing Larke Huang from the Substance Abuse and Mental Health Services Administration.

DR. HOULE: I'm Gail Houle, and I'm with the Office of Special Education Programs, the U.S. Department of Education.

DR. JANVIER: I'm Yvette Janvier. I'm a pediatrician. I'm board certified in developmental behavioral pediatrics and neurodevelopmental disabilities. I work in central New Jersey. I have a practice of over 1,000 children with autism. I'm one of the public members.

DR. van DYCK: Good morning. Peter van Dyck. I'm director of the Maternal and Child Health Bureau in the Health Resources and Services Administration.

MS. REDWOOD: Lyn Redwood. I'm with the Coalition for Safe Minds and also the National Autism Association.

MS. BLACKWELL: Ellen Blackwell. I'm with the Centers for Medicare and Medicaid Services, and I also have a 21-year-old son with autism.

DR. LAWLER: Cindy Lawler. I'm a program director at the National Institute of Environmental Health Sciences and have responsibility for the Autism Program at our institute.

DR. RICE: Hi. I'm Cathy Rice with the National Center on Birth Defects and Developmental Disabilities at CDC. I'm sitting in today for Dr. Ed Trevathan, and I work primarily on our autism surveillance projects.

MS. SINGER: I'm Alison Singer. I'm executive vice president at Autism Speaks. I have a 10-year-old daughter with autism and a brother with autism, who turned 44 yesterday.

DR. ALEXANDER: Good morning. I'm Duane Alexander. I'm a pediatrician and director of the National Institute of Child Health and Human Development at NIH.

DR. WAGNER: I'm Ann Wagner from NIMH, and my role here is as exec sec of this Committee.

DR. INSEL: Welcome to everybody. I'm Tom Insel, the director of the NIMH and chair of the IACC. Our first order of business is to review the minutes from the first meeting. I will take comments, revisions, edits, concerns, and anything there. I think you should have received these ahead of time.

[No response.]

DR. INSEL: Hearing none, I will assume they are approved.

Let's move on, then, to the first discussion, which has to do with picking up on a thread that we had from the first meeting. If you will recall, there was a fairly lengthy discussion at the first meeting about trying to find a balance between the research strategic plan, which is part of what the Combatting Autism Act called for, and the need that many people on the Committee felt for some attention to issues around services, which are also in the Combatting Autism Act but hadn't been included explicitly as part of the Autism Research Strategic Plan.

We resolved that to some extent by saying there are aspects of research which can inform services and that part of it should be incorporated into what we do with the strategic plan.

But there was also a sense from many of the people around the table that that just wasn't going to cut it, that we needed to do more than that, and that there was an opportunity here to pick up on something that we had started in the first IACC, which was to look at the landscape of services and to ask how is this working, where could we potentially do more, and how could we use the IACC to inform that process.

If you will remember, the Combatting Autism Act talks about using the IACC to give the Secretary of Health and Human Services information that he or she may need in guiding both the provision of services as well as the conduct of research.

With that in mind, there are three people who I thought really spoke up most at the first meeting about this: Larke Huang, Lee Grossman, and Ellen Blackwell. We have approached each of them to ask them to help bring this back to the table and have some discussion with us as a group about where should we go from here, how do we want to handle this issue, and what should the IACC be doing in this arena.

Lee, would you like to start the discussion about this and maybe, with Ellen, we can see how the group wants to deal with this particular question.

MR. GROSSMAN: I have some slides.

[PowerPoint presentation.]

MR. GROSSMAN: Thank you. Good morning, everyone. It is very nice to be here and to have this very intimate discussion with all of you about the services and where the IACC should be heading. There has been a lot of activity that Ellen and I have been involved in over the last two weeks when we were pegged. I guess I have to somehow figure out that maybe I should keep my big mouth shut sometimes so that I wouldn't be put in this position.

It was a hard position to be put into because I had reservations about doing this. I consulted with a number of friends and confidantes on this. One of the people that I didn't include my wife because she would have immediately told me not to do this. She is a better judge of my character than I am.

But the people that I did talk to about being the co-chair of a resurrected Services Subcommittee put the challenge out to say if we are going to do this that we need to make it meaningful. We need to make it something that will address the urgency of the issue. It is within that framework that Ellen and I started to work to do some sort of presentation to put some balance and put some thought behind this.

By no means, what Ellen and I are presenting today is anything definitive or directive. As I said, this is really an intimate discussion that the IACC needs to have so that the IACC, as has been explained to Ellen and I, can make the decisions on how it wants the vision and the direction of this Committee to move forward.

What I'm tasked to do here right now is to give you a background on where we are and what the IACC's activities have been heretofore. Part of my decision to go forward as co-chair was based on the activities that the IACC has done over the past couple years because I firmly believe that there is a foundation there that is perhaps one that is the best available at this time to move forward from.

With that said, let me go into a historical perspective of the IACC's activities in dealing with the services and the Services Subcommittee.

When the IACC was first formed in '01, there really was not much involvement of services at that time. Dr. Hyman was our first chair of the IACC, and then when he left to go to Harvard, Richard Nakamura came in and did an excellent job of leading this. But the service agencies weren't well represented on that. There was, again, this discussion, as we are having now, of how do we bring that into this dialogue.

We started getting HRSA, SAMHSA, and some others brought to the table. It was interesting at those first few meetings where those agencies were even questioning aloud. They were questioning in an open forum what were they doing there because they didn't know what they had to do with autism. So it was time to act on that.

There was a presentation that I did in '03 that outlined the agencies in terms of what they were doing very specifically right now in spending the billions of dollars in service delivery in this country for autism. The summary of that talk is what you see in this slide, which is that everybody was operating in silos. People were not aware of what others were doing. People weren't even aware in their own agencies what their agencies were doing.

The take-home statement from that was that we needed a dramatic, proactive, aggressive, and coordinated response from multiple federal agencies to move forward on this.

Quite happily, the people at the table really did get it. The subcommittee was formed. It was headed up by Cybil Goldman from SAMHSA and Meryl McPherson from HRSA. They got started working on pulling a very, very great document together, and I believe in your packets is the summary draft of it, the Autism Spectrum Disorder Services Roadmap.

In 2004, there was a series of meetings of the subcommittee, and an expert workgroup was formed. These were the people that were on the expert workgroup.

[Indicates slide.] They represented service providers, experts in the field, some parents, and people on the spectrum. We sat down and put together an extremely well documented, comprehensive life span roadmap.

I think what you have here is a 17-page draft of that. I have the original draft, which was actually 31 pages, and there are addenda in that. I will be happy to make that available to the Committee. In those addenda there is even more information in terms of action plans for developing this forward and making it even more meaningful.

The emphasis throughout, which is wonderful, is on best practices. There is nothing that is in this that doesn't meet the standard of what we would all want. It is an incredible document.

I have been saying that there are about a hundred bullet points in there, each one of which required its own white paper to develop so that we could fully understand the service needs and how it needs to be developed. I finally sat down yesterday morning in preparation for this and counted the bullet points. There are about 270 bullet points in there. So as you can see, our work is cut out for us, but it is a living document that I think that we can expand on.

The gist of that roadmap is here in what the expert workgroup concluded were the urgent, cross-cutting themes and recommendations. That first and foremost was to address the urgent need for services across the life span, to coordinate these services at multiple systems levels, [and to] increase the provider capacity. It is one thing having the services, but really what we have in the United States today is not a method for delivery of those services, because there are very, very few providers out there.

[Also] obviously, to develop standards of care and expand the private and public funding for these service mechanisms. We also have to identify and have this relate directly back to the state and local communities so that it is meeting the local needs.

What I have found to be most dramatic about this roadmap is in its preamble, its first few paragraphs. I use this in many, many talks that I give, where I let the community know that the federal government has identified, and it is all stated here, the issue at hand, and that there is an acknowledgment by the federal government that action needs to be taken.

I love the last sentence, "Thus we must respond by developing community systems that are integrated across service sectors and are collectively responsible for achieving appropriate individual, family, and community outcomes." Wonderful document, wonderful preamble, wonderful action plan.

Again, for this resurrection of the Services Subcommittee, we have an incredible foundation to work upon. How it has been explained to Ellen and I, and Ellen is going to go a little bit more into this, is that the Services Subcommittee will be made up of only IACC members. That doesn't preclude us from forming an expert workgroup, or we can expand from there.

Some of the recommendations that I want to bring forth is that we did have a wonderful expert workgroup, but in our work we have identified so many other groups that represent federal, state, and local providers as well as individuals that are wanting to work with us that are actually going to be the people that ar going to be implementing these services.

With that said, if we are going to form an expert workgroup, we should expand this. We could, maybe, set up a number of separate workgroups as well. It should include people as those that we are currently, at ASA, collaborating with now in developing service plans and developing standards and best practices. These are just but a few of probably about 50 organizations that we are working with hand in glove to move forward.

Some of the groups that are missing from this that can easily be brought to the table in terms of an expert workgroup are insurance agencies, for example. Large corporations that have large health plans can be brought in. We have identified a number of those that are wanting, willing, and able to participate in this process as we move forward. It will be up to the IACC to decide how we are going to do that.

Really, a day doesn't go by where I am [not] personally humbled by what we are faced with. Even this morning people were pulling me to the side and challenging me and challenging the IACC to act, to respond to the urgency of the time and the need in the United States to address this incredible national health emergency.

So I put before you these two essential questions that, if it is not us here at the IACC, then who will it be? And, if it is not now, when will we do this? I look forward to the discussion. If people are looking for more specificity, if that is what the Committee wants, I think Ellen and I are happy to supply that. We will reserve comment until we get to that point. Thank you very much.

DR. INSEL: Thank you, Lee. Ellen, do you want to add anything to this?

MS. BLACKWELL: Sure. I think our idea was that Lee was going to talk a little bit about the work that the previous iteration of the IACC did on services. I came in at the very end of that group, so I'm not as familiar with what took place, but obviously a lot of good things came out of it.

Dr. Insel, Lee, and I talked about the fact that we think that the language in the act asks that we talk about access to services and supports for individuals with autism spectrum disorder, that we make recommendations to the Secretary, and I think that we can construe the word "research" on autism as broadly as we believe necessary. There is a lot of flexibility in this act.

At our last meeting, when we separated our research into these four categories, we agreed to put services and supports under this rubric of treatment. Joyce is going to talk a little bit later this morning about what happened at the scientific workshops that were held in February, but we did have a workshop on treatment.

Prior to the time we convened these workshops we solicited a request for information. This is one of the ways that the government asked the public what do you think. It is interesting to me that about half of the 500 responses were related to treatment, and a lot of them came from organizations and entities that represent many, many children and adults with ASD.

When I looked at those responses, I tried to categorize them into certain service issues. When I looked at it, I saw these issues coming up over and over again: the economics of ASD across the life span; the need for evidence-based services for children and adults -- Lee mentioned that -- provider training and qualifications; adults with autism who do not have intellectual disabilities; the transition to adulthood; the employment of adults with ASD and vocational training; community inclusion of adults and children with ASD; health and safety issues; family supports; unmet needs and system gaps; and assistive technology and environmental modifications. Those really stuck out in my mind when the RFI came in as the categories that were directly related to services.

When we met on the 21st of February, the treatment workshop convened. Again, part of that was services and supports. It was a really interesting day. It was just a stellar group of 17 people. I'm still amazed [what happens] when you put really smart people together and you tell them to come up with something really quickly. This group did an amazing amount of really good quality work in eight hours.

It included providers, researchers, academics, advocates, federal representatives, physicians, and scientists. To me, two of the big themes that came out of that day were that we really need to take a look at services for adults, [who] have been a very neglected population, and second, that we have to start talking about autism across the life span. Maybe we have been talking a lot about children.

That particular day, six out of the 10 what I think of as mini requests for proposals seemed to have an intersection with services and supports, and 13 out of the 41 proposals that came out of all four of these workshops had similar themes. That is pretty compelling evidence that we need to do something.

The next thing I want to mention is that there are a couple people here today that I think it is just terrific that they are here. One of them is Barbara Edwards, who represents the National Association of State Medicaid Directors, and the other is Nancy Thailer, who is sitting back here. She represents the National Association of State Directors of Developmental Disabilities, NASDSE, one of the worst acronyms ever, Nancy.

[Laughter.]

MS. BLACKWELL: Both of these women are just fantastic advocates and represent hundreds of thousands of beneficiaries and people with autism. Just the fact that they came here today to listen to us talk about services is amazing.

CMS has been very busy lately issuing regulations, and I'm pretty sure we have kept both of them up at night. I know we are keeping them busy during the day. But, just the fact that they came here today to support our efforts is very telling.

So, where are we today in terms of autism services. This is just amazing to me. We really do not know. So if we don't get a baseline for where we are today, how are we possibly going to know where we are in 10 years.

I brought with me this wonderful book, The State of the States of Developmental Disabilities. This is the brand new version. I can pass it around. Wouldn't it be amazing to see something like this on autism? How can we tell where we are to be if we don't start taking a measure.

The second issue to me is that we really don't know what services and supports help children and adults the most because we have very little information. Shouldn't we try to figure that out so that we can use our dollars wisely and purchase what works.

I was thinking the other day, and I was talking with Ed Trevathan, our member from the CDC, about medical models. If you look at services, we don't use a medical model. We just try to do no harm. We don't have a protocol for children and adults, and it is just very mystifying to me in this era of value-driven health care. We really are responsible for providing services that are grounded in evidence. We should know what a good model looks like for children, and we should know what a good model looks like for adults. Shouldn't that be another part of our goal.

We have such energy and commitment. I work with states every day, and I'm just astounded at the effort on the ground to try to figure out what does the landscape in my state look like.

So we have all these fractured, duplicative efforts. We don't have any national effort to look at supports and services. As Lee said, who is going to do that if it is not us.

I also think that it is really important to look at preventing autism and ameliorating autism, but we have a duty to look at supporting the people and adults who have autism today.

So that is where we are. Lee mentioned that we are a committee that is under the Federal Advisory Committee Act, so there are some rules that would attach to anything that we decide to do. I think what we are proposing today is that we create a Services Subcommittee. That would have to be made up of IACC members, which certainly doesn't preclude us from bringing in consultants and others to help us.

We talked about the possibility of having a series of town hall meetings to solicit individual opinions. I was thinking last night we might want to put out another RFI to solicit more public opinion. It really depends on what you all want to do.

With that, I am throwing out the discussion to you guys and you can weigh in.

DR. INSEL: Great. Thank you. Let's open this up, then, for broader discussion. Cindy.

DR. LAWLER: Can you talk a little bit about the impacts that the availability of the recommendations from this initial roadmap has had? Are there lessons learned about, maybe, implementation issues surrounding those recommendations or strategies to overcome those same obstacles if they are going to arise in the continuation? This is a very carefully considered set of recommendations, and I'm just curious as to whether this has had impact thus far.

MR. GROSSMAN: I'm glad you asked. That is a great segue to what has been the impetus behind a lot of the discussions that have been going on from this first draft, or the acceptance of the Services Roadmap.

It has been difficult to move things forward because we just don't have the data. We don't know what to do, for the most part. I think anecdotally we all have a very, very good idea of what needs to be done. Actually, from my perspective, we are already there. We know what needs to be done to service this community. We know enough about early intervention. We know enough about early medical intervention. We know enough about service delivery on the psychosocial, behavioral, and educational side. But it is all anecdotal. Nothing has been proven.

As a result, it is hard to get traction when we go out and get funding for that. It is hard to get the insurance companies to support it. It is hard to get legislation passed. So a lot of effort has been put forth over the last probably two years pulling some of the things out of the roadmap.

This seems like, at least from the discussions we have had, the genesis for a way to move forward. This is something that Congress is even considering right now. Not only doing the studies like Ellen was saying, to come up with a booklet that really shows what the service provision is, but to also put into effect demonstration projects to prove what we believe anecdotally now.

Personally, I'm coming at this from the standpoint that we do know enough about how to service this community now. So I would like to put this out on the table that it is not an issue of knowing, it is an issue of accessibility. There are some people out there that get excellent services. It is probably 1 or 2 percent of those that are affected by autism, but they do get excellent services. It is more of an accessibility problem. We need to prove the concepts and then make them available to everyone who is affected by this.

But anyway, I'm just throwing this out as, maybe, a point of discussion. The Committee should rip it apart as they feel needs to be done. The main criticism that we have gotten on this suggestion is that it just doesn't do enough.

MS. BLACKWELL: I would even add that we don't have any models for adult services. In our home and community-based waivers, adults with autism are generally put into products for adults with mental retardation and developmental disabilities. There is no model for adults. We have a few waivers that serve children but they are not very comprehensive.

We couldn't even put together a demonstration grant without at least getting some idea of what that model looks like. We need to go back to that before we even start talking about the grants. I'm sure states would be happy to come in and say, we would like to try this, that, and the other thing, but we don't really have any evidence or any collection of data showing what that should look like.

DR. INSEL: Yvette.

DR. JANVIER: It just reminded me of the situation with ADHD and looking at medications with psychotherapy versus community care. So when you say "demonstration project," there are models in the medical and child psychiatric world looking at an ideal treatment, what is happening in the community, and then no treatment, or whatever.

The other thing is it is very hard not to give any intervention. My two cents; I have seen children get the perfect, ideal treatment and they may not have done as well as children that got okay or minimal treatment.

The group that I was involved in was the diagnosis group. We were talking about trajectories. We need to figure that out. Who is the average child with autism from age two to six and who is the child who is going from not talking at two to mainstreaming and how did they generally get there. I think that is very critical.

I think you can't abandon the research concept, but the services or treatment or however you would like to characterize it has to be looked at in an objective research model in order to show validity.

DR. INSEL: Cathy.

DR. RICE: I would just add that in terms of the other activity that we are going to be doing today, looking at the research goals and moving forward on the research plan, I think there were some encouraging perspectives in the goals that were put together for the research plan. Research can also include not just let's evaluate the models and what is effective for what age or what type of individual, but how does community implementation happen.

[We should make] sure in our research goals that we are looking at the implementation as part of those research goals and that we also have a research system that links to services so that we have a way to look at the new and emerging treatments that are coming up so we can rapidly, effectively, and carefully evaluate them. Then, include that step to make sure that they actually get into practice when they are effective.

DR. INSEL: Gail.

DR. HOULE: I'm impressed with the ideas that you have put out here. I certainly see that there could be, with many of these ideas, a good partnership with the educational service provision component. National Technical Assistance Center sounds like a place to start to actually implement some of the research-to-practice and the implementation challenges that are faced out in communities and states.

I wanted you to know that you have our support and my support as you move forward in working on many, many of these ideas that you have put forth in here.

Certainly, parent-professional-school partnerships are a great area for service collaboration and some of the conversations that need to take place for the best practices to be implemented. I would put in all of those -- and I know that you are a family member and so you know very well -- including the family, and it probably goes without saying, as important partners in every activity that the Service Committee and that the service recommendations put forth.

DR. INSEL: Stephen.

DR. SHORE: Just one little addition to that: also including, where possible, people on the autism spectrum. We have a good idea of what we need.

DR. HOULE: I didn't mean to slight that. I work generally with young children.

DR. INSEL: Peg.

DR. GIANNINI: It has been mentioned, I think by Ellen particularly, that we should look at this as a life span problem. I think that might be a good framework to start since we are grappling with where and how and when to approach the issue. The various milestones of life are the different needs and gaps that really impact this community.

If we plan on the life span approach, then we can focus on the domains that are particularly important for the milestones in that individual's life. Early on we know it is health and it is education. Then it is employment. The services and access and availability would become seamless.

I think the struggles have been all these years that it has been so fragmented that there is no continuity of care for these individuals and their families. So I would support the idea of a life span approach if we can think of it in that way.

DR. INSEL: I'm listening to this and trying to make sure I understand what we are really talking about because it is not clear what the deliverable would be from this effort. We already have a document that looks very good that was put together in 2005. Many of the issues that people have brought up, some of these issues, were addressed at that time and were laid out with some of the needs.

I guess, to go back to Cindy's original comment, I would like to hear how people see us going beyond what we did in 2005 and what it is you really want to have come out of this. I heard, for instance, the State of the States document would be one option.

Ellen, I remember when you presented to the IACC I think it was in 2004 and you went through the complexity of the services landscape and the huge diversity across states and how people were moving from one community to another to get different kinds of services. It was just overwhelming but also tremendously important to find a way to capture that. It is not going to be in the research strategic plan; I can tell you that. That is a different set of issues.

So, is there some way to make that more accessible, to have the IACC have some impact on that so that if we have this same conversation five years from now we are not just saying, well, we have a really nice document that is in your packet that you can look at. Tell me about the deliverables.

To go back to Lee's comment, if this is the time and we are the people, what are we going to do? What would you like to see come out of it?

MS. BLACKWELL: I already brought up the State of the States. It seems like such a basic thing to me that we have to know where we are by state because where you live in the United States is the best predictor, whether you are a child or an adult, of your quality of life. It varies vastly from state to state.

When children are young, they get mandatory services through the education system, but when they finish, generally around age 21, they end up on these very, very long waiting lists for discretionary services that are at the state's discretion. They wait for years and they are not transitioned smoothly. Sometimes a crisis can precipitate being put into a program. It is really a very disjointed system for both the person with autism and his or her family.

So, not just the look, I think, the snapshot of where we are, but also I think we have to take a look at what we know about adults. We don't have one single waiver program for adults with autism. What does that mean? We don't really know how they are doing in these MRDD programs and if they are even the right thing. Maybe we need to take a look at what would a good model look like, especially for adults. That is the population that I really worry about because they don't have mandatory services. What do you think, Lee?

MR. GROSSMAN: I think everybody is quiet because this is such a hard, sobering topic. This is where the rubber hits the road. This is what we are trying to implement.

Research is one thing. We could do bench research until the cows come home, but people need services today. The urgency is incredible. The hardship and the crises that this has created are beyond imagination. So it is time to act.

I think that we do have an excellent document in place. I have gone over it many, many times, and I personally have found it hard to improve upon. So we do have a foundation that has brought people together to look at this.

I think it is time to start chipping away at that, putting together people that will take aspects of that in terms of looking at it from a federal, logistical standpoint in expert workgroups that will then come forward with business plans or plans of action. I'm not really sure what kind of terminology to use, knowing that this has to fit into a federal, mandated protocol. But, [to] really proactively look at this and then turn it over to the advocates to run this up the pole to get legislation and funding for it.

I realize that that is where we are now. We have a federal budget that hasn't accommodated for this. At some point it is going to have to be paid for.

Ellen and I have debated this a number of times. It is not like we are not spending money now. We are spending billions, if not tens of billions of dollars out of the federal budget every year to treat this population. Yet it has had tremendously little impact.

So we have to make this more meaningful.

I know I'm talking in generalities, but I think that is where we are right now because we need more specificity from the Committee in terms of how they want to move forward on this.

I will emphasize, though, that as much as research is important and as much as research needs to be part of anything we do so that we can define this, that should be a secondary consideration. The primary consideration is that there are people out there that need services today, need them now, and all of what we do in terms of how we direct this should be geared in that manner and that fashion.

As I said before, we know enough now to help people. It is a matter of accessibility and getting it to them. We need to find mechanisms to prove that and to show that it does work.

DR. INSEL: Pat.

DR. MORRISSEY: I think I endorse or support everything I have heard so far. I would just like to throw out a couple ideas and also to pick up on your point, Tom, about what do we do. The National Defense

Authorization Act of 2008 I think authorized autism centers for military families. I don't know how much money was appropriated, but I think it was $6- to $8 million. That is one issue that is out there.

What is happening is there is attention to the topic of autism and people in Congress are putting money with it. The thing that is not on the list up here on the slide is the capacity of communities or the military to even take advantage of that money in a thoughtful and practical way. So I think that training and training materials, known or to be developed, need to be suggested.

The other thing is, I think that, as Lee said, there are a lot of good ideas out there. I can think back to 1990. Congress basically gave the Department of Education a million dollars and said put out the best there is on attention deficit disorder. At that time, that was a lot of money for one thing. There were booklets that went all over the countryside: doctor's offices, training programs, and higher ed. I think that is another strategy that could be somehow recommended.

The third thing is a general comment. I think that we need to be a catalyst to affect the behavior of others. That could take a variety of different forms. Power doesn't exist unless you exercise it. So we [could] take a position on something to inspire others to collect and to make available to the public the best there is on what we know. [We could] also, as Lee said, encourage somebody to create workgroups to deal with the issues that need more thought and attention, like how do you serve adults.

There is a woman named Ruth Sullivan, who I think is about 82. She lives in West Virginia. She has come to see me about three times. One time she brought me a pair of shoes because she knew I like black shoes with straps. She has been advocating for a very long time for support for training materials.

She has a cadre of five community-based rehab programs that focus on adults with autism, and they want to develop training materials so that they can get the word out. She is a constituent of Senator Byrd, and she was not successful in getting his attention.

What I'm saying is that all these things are frustrating but I think that there has to be just one big push, and that can bring a lot of people to the table. The strategy that everybody is using is the academy. You bring people from five different programs to the table to talk about a topic in the state and then they all go back and implement that.

I have seen it firsthand in emergency preparedness. I know a lot of work has been done by CDC with regard to young children with autism, bringing all the players in a state together and talking about what we can do together to make things different.

So the pieces are out there. Maybe we just have to have a very loud voice and cause some of these things to happen.

DR. INSEL: This goes back to Lee's comment and his first slide about part of what we can do here is coordination as well as this catalytic function to make sure the information is brought together in one place.

Your comments remind me that Jim, Duane, and I had a rather informal meeting with the appropriations committee this week on the House side. The chairman of the committee, David Obey, who is from Wisconsin, made an interesting comment to us. He was telling us about one of his constituents, who is a woman with two sons, one of whom was an adult with autism. The other was an adult whom she had always thought was going to care for her autistic son when she died.

The week before, she found out that her non-autistic son was killed in Iraq. So she came to Congressman Obey saying what am I going to do? He brought this to us saying, what should I tell her?

It reminded me that there is a whole area here that we do need to really push on in a way that has more visibility. We often say at NIH this is the area that can inform policy most directly. There are so many policy issues here. The problem is that so many of them have been at the state level and there has not been an opportunity for giving a federal push to get some kind of consistent state evidence.

Jim.

DR. BATTEY: In listening to the discussion around the table, I'm struck by the fact that perhaps there is a need for clinical studies to validate the fact that specific intervention strategies are efficacious for two reasons: one, because they will inform you in a systematic and scientific way about which strategies to employ for which individuals at which age; and finally, I don't think there is any way you are going to attract money from third party payers or the government to support these services if you don't have the evidence that they are in fact efficacious.

I would suggest that that is an interesting place to start. You may ultimately be able to show that in fact the interventions are cost effective in the sense that by rendering individuals more productive and more employable that at the end of the day the government saves money rather than spending more money.

The healthcare sector is growing at 10 percent a year. It is already 17 percent of gross domestic product. There is no way we are going to stem that tide without figuring out how to intervene not just in autism but in a whole spectrum of different disorders. We have to do that.

MS. BLACKWELL: In fact, one of the more interesting proposals that came out of our treatment workshop, Jim, was a proposal to mount a cost outcome study on services.

DR. BATTEY: We did that for the cochlear implant a number of years ago. Actually, we supported the effort. It was done by John Naparco, who is an otologist at Johns Hopkins, a very distinguished young otologist. It was very straightforward. It showed that although the implant surgery and the device is very expensive -- it costs on average about $55,000 per child -- that if you compare that with the cost of educating these kids in schools for the deaf and lost income over a lifetime, the implant surgery is a bargain.

It was at that time that we were able to begin to get more meaningful involvement from third party payers to help support implantation.

DR. INSEL: So, what is the wish of the Committee? Should we charge a group here to come back to us at the next meeting with a plan for what this might look like? If so, who would like to be on this group? I'm assuming that Lee and Ellen have volunteered. They both sigh as I say that, and wince. Stephen.

DR. SHORE: I will volunteer to be on that group.

DR. INSEL: Terrific. Anyone else? Peg,

Chris? Okay. Pat, and we have Peter and Gail and Cathy. Excellent.

DR. RICE: I have a question to your deliverable question. If we have an official subcommittee here, don't we have an opportunity for a deliverable to be possibly an implementation report? One, if we agree that the roadmap that was put together was an excellent start in terms of the comprehensive plan that is needed, a next step would be what are the details of how do we get this to happen.

We have these different aspects of the long-term goals of making sure that the treatments that are put into place are evidence-based, but we have the immediate need about billions of dollars are being spent and there is more we could do to coordinate the care that already exists. Both of those levels are integrated in here in terms of the plan that has already been put forth.

So I would just propose that a deliverable would be the specific implementation of the document, one, if the Committee agrees that this is an excellent place to start; two, then going through the details of what it takes in terms of agency coordination, other organizations to coordinate, what types of committees report things for each of these different points, and how much it would cost.

DR. INSEL: That will be part of the discussion. Duane.

DR. ALEXANDER: I would like to endorse what Catherine just said as a procedural step. It sounds like you have an excellent document to start with, but it still is almost four years old. Probably, a first step for this group should be to figure out a way to get an update on that and make sure it is as current as possible. Then, take that document and turn it into an implementation plan with specific, prioritized steps.

I would also encourage them to identify what components of that are researchable or in need of research to try and identify the most effective interventions or compare effectiveness of different interventions.

Your list of topics up here, Lee, looks like an excellent list of things that the agencies and others could do as implementation kinds of steps. It would seem that that would be a logical course for this working group to set forth.

DR. INSEL: Chris.

DR. McKEE: I just want to mention that several people have talked about the mandatory services for kids. Actually, looking through the roadmap, there is one area that talks about the interventions being well defined and therefore we really need to focus on adults. I'm not at the adult stage yet, and I'm horrified by what I have heard about it.

But, just to give some people an idea of what is going on with our children, I'm in a community that is trying to get discrete trial services in the classrooms. The way that they are doing it is they are completely segregating our children into small teacher-ratio classrooms and not allowing them outside of those four walls. The least restrictive environment, the idea behind the IDEA, the Oldham decision, and everything else that talks about community-based services has gone to the wayside.

To the extent that these interventions have not performed the miracles for all of our children that

Yvette was talking about, we have ended up with a bunch of children isolated from anybody but the worst-behaved peer models, and that is where they are going to stay in our elementary schools.

I think it is important to get out there, get the State of the State, figure out who is doing this better than we are doing it here, and then shop that model around. Although we can have all these studies about interventions -- a lot of people have compared autism to cancer -- they are not going to work across the board. We have many different types of autism.

Anyway, I want to make sure that the focus doesn't leave our children because, although we have these great models and we have made these great strides, I would be hard-pressed to find a parent who is content with the situation of their children in school these days.

DR. INSEL: Well said. I guess the only piece I would add to that, Chris, is that what we are hearing is that even when the structures are there, the people aren't. Place, including wealthy counties, simply don't have the capacity or the work force.

Lee mentioned this in his early slides. There is such a mismatch between supply and demand. I don't think that has been captured well in numbers. We hear parents complain about it all the time and we hear about families moving from one state to another state to get better access, but those are anecdotes. I think that is something you don't see so often with cancer. Sometimes, but not that often. We shouldn't be in this position that what you get depends on where you live to such an extent.

Gail, last comment. Then I think we will move on.

DR. HOULE: Yes. I agree, also, with what you said. Did you volunteer? Are you on the subcommittee? Good, good. I too would like to not lose the focus on children. The dearth of qualified personnel to implement the services, even when the services are well defined, is a problem that we certainly know about and have been trying to address.

We have not, at the Department, at the federal level, been able to successfully address it, but we do have some data. We do have some new strategies that we are trying to get states to use in the state and in the community for recruitment and retention of qualified personnel to work with children with autism.

I think that this is an area that we can contribute certainly an informational base, maybe resource communities, maybe identification of resources, and get them out there through the IACC. So I'm really glad that you pointed that out and that you are on the Committee, too.

DR. INSEL: So the charge would be that at the next meeting this group will come back and give us some ideas of what an implementation plan might look like. I like the word "catalyst" that Pat used, ways that we could turn what we did in the original committee into more of an action plan and to think about where the opportunities are.

Thanks to so many people for volunteering. I think Lee and Ellen had this moment of feeling like this was going to be all on their shoulders and they have lots of great help, so we will look forward to a follow-up discussion.

MR. GROSSMAN: With that said, Ellen and I are assuming you are going to provide us with a staff of 20 and unlimited funding to do this, too, right?

[Laughter.]

DR. INSEL: Only 20. We were thinking at least one person for each state. Good luck.

[Laughter.]

DR. INSEL: We are a bit ahead of schedule because we got started right off on this discussion. Joyce was going to take us up to date on the strategic planning effort. We can either take a break now and do that afterwards or start with her presentation and take a break after her presentation. I would vote that we keep going for another 30 minutes, if that is okay with the group. I see heads nodding.

Joyce, are you ready to go?

[PowerPoint presentation.]

DR. CHUNG: My name is Joyce Chung, and I'm a psychiatrist working on the Autism Team at NIMH. The rest of the team is back right where I was sitting over there: Steve Foote, Dan Hall, and Diane Buckley. We work with this Committee and staff it. We are not 20, but we are a strong four or five.

We have been involved with the strategic planning process for this Committee. My job today is to report to the Committee about the progress we have made on developing the strategic plan for ASD research according to the process that we approved back in November, at the November 30th IACC meeting.

This is just a progress report. We are going to have a full discussion about steps from here, but I would like everybody to know, including the public, what we have been up to.

I presented this slide back in November, which was really how we envisioned a structure for making this plan happen. The Committee is, as you see, a large and diverse committee and has public membership. A third of this Committee is composed of non-federal, public members.

This parent body, the IACC, is represented at the top of the diagram. Underneath it is the workgroup that was formed out of that process approval in November, and the Strategic Planning Workgroup was envisioned as a temporary group that would help this Committee deal with the details of establishing parameters and a process and making some decisions for the Committee. That is the second box below.

Beneath that as well were then four scientific workshops organized into these topic areas: biology, diagnosis, treatment, and risk factors. These were basically our attempt to carve up the research in ASD into manageable chunks.

Again, our team was responsible for staffing the IACC and workgroup. We also help manage and organize logistics for workshops.

We have always thought, while they are not in this diagram, that stakeholder involvement -- and that is very broadly construed -- was critical for this process to be effective.

We have been very busy. Since November we have completed these steps. What we basically did was soon after the approval of the process Dr. Insel, who chairs this Committee, formed a Strategic Planning Workgroup. I will tell you more about that later, but that workgroup just convened around a conference call in December and began to set plans in motion.

Practically at the same time, our team wrote and sent out an electronic stakeholder request for information, an RFI, which went out in December. We received responses through the early January time period. We sent this out to the larger community, and I will say more about that in a bit.

We also began planning for these workshops, which were in mid January, only about six weeks after that November meeting. So we were just in a big rush.

The latest step we completed was a meeting of this workgroup, a face-to-face meeting, about three weeks ago.

This is the timeline that I presented in the fall. We have really pretty much gone through all the parts in blue, as I described. We are in this transition zone in the middle, the yellow area. We have slowed it down a little bit. We haven't actually set priorities for the initiatives that came out of the workshops. We can discuss that further today, but just to give you a sense of where we are in this timeline.

When we talked about this process in the fall, we talked about a six-month process to have a deliverable of a draft plan by May. That may be pushed back now, but that was the original plan. Basically, this gives you a sense of where we are.

I think a lot of people are curious about the stakeholder RFI. I have to say that this was an incredible opportunity for us to hear from many different people. The title of the RFI was Research Priorities for the Interagency Autism Coordinating Committee, Strategic Plan for Autism Spectrum Disorders. The purpose that we stated there was to seek input from ASD stakeholders about high-priority research questions as a first step in receiving broad input at the beginning stages of strategic plan development.

In doing this RFI, we asked respondents to provide input into each of those four separate domains that we had planned to use in the workshops: again, biology, treatment, diagnosis, and risk factors. We asked people to weigh in in those topic areas.

We posted this RFI in the NIH Guide on December 19th and only had about two and a half weeks to get responses in, which was very short. If we had had more time, we definitely would have wanted to hear even more, but we got a tremendous response. So while it was short, people got it.

What happened was with this age of the Internet we got this out and pushed out widely to advocacy organizations, research and professional organizations, and through a listserv and so forth. I think people did a tremendous job in pushing this out to the wider community.

Also, we had some key organizations like the Autism Society of America and Autism Speaks, who prominently put the RFI notice on their home pages at a critical time. Again, this was over the holidays, so you can imagine we were worried that we wouldn't get much. But, we got a tremendous response. A lot of bloggers who really have their finger on the pulse of what is going on out there were really active in getting input, so we got a lot of responses.

Again, we had, technically, 542 responders, but within those there was a tremendous amount of content, so we can't say there were just 542 ideas. It was many, many, many ideas within any given response.

Interestingly, we didn't ask for information about people's personal backgrounds but people offered that and provided that. We were able to glean some information about who these people were by the information they provided.

We really got a lot of parents or families. We had a lot of grandparents who wrote in. That was really very interesting. We also had many individuals self-identified with an ASD who wrote in as well. We had professionals from practically every related field involved with ASD care, whether it is speech pathologists, nurses, physicians, specialists, and so forth. We also had many people from the educational side, school staff who weighed in, and also a lot of researchers, who are clearly also stakeholders in this process.

We had people who also gave an institutional affiliation for where they came from. We had state autism societies from many different states. We had local or state departments of health, mental health, and public health, university departments, very specific disease foundations that might have an autism type symptomatology associated with the disorder. We had the advocacy organizations of all types and sizes, and professional organizations. So this was, again, a very broad swathe.

In terms of the geographic distribution, we received responses from practically every U.S. state that we could gather. These were even the people who mentioned they were from rural Wyoming or from Hawaii or Maine. We got them from practically every corner of the country. It was incredible to see that.

We also received responses from military families who identified themselves as such, and certainly foreign countries. There is nothing to stop someone from weighing in from Norway or Argentina, so we got that as well.

As Ellen mentioned, the treatment domain of those four domains received the largest proportion of responses. I think what is interesting about the treatment responses is, even though we had a high volume, it wasn't like we had a lot of repetition of the same ideas. There is a tremendous variation in what people think is treatment and what is intervention and services.

So there is a lot to talk about and there is a lot there.

Again, volume doesn't mean that everyone just weighed in on the same area. It was very interesting in terms of the diversity of responses there. We got people who really said totally opposite things. I'm not going to go into that, but you can imagine people thought one thing and some people thought the exact opposite. So there we go. Diversity right there.

Obviously, people who responded thought research was important, so they generally had very strong support. We provided pretty comprehensive, lengthy summaries of the RFI responses to all the scientific workshops. That is what I'm going to talk about next.

I wanted to make sure that you understood that despite the short time frame and the hurried nature of this we got a very strong response that is very rich. I hope that the Services Group will take a good look at this information as well.

I'm going to move over to talking about the workshops that we conducted. Again, these were conducted in these four areas. We held them on four consecutive days in mid January. The purpose of doing them together like that was because there was thought to be meaningful overlap between these groups. We didn't want to have silos, as people can criticize science as being in silos. There needed to be a lot of cross-talk.

There was an attempt to really have some overlap between groups, not just in membership of some of the participants. Some people stayed over to observe. We had some cross-cutting themes that the chairs wanted to consistently emphasize. Those two ideas were the idea of heterogeneity of this disorder and also the idea of trajectories. This is a life span issue and we can't think just about one particular point in time. It really is something we have to think about very broadly in a very life-span focus.

We worked these groups very hard. They worked very, very hard over a long day. We didn't even let them have a lunch break, actually. They worked very hard, and they produced a set of what we are calling research initiatives, essentially a template that we forced them to use. [It was] a PowerPoint slide where they had to specify what specific sorts of research questions they were interested in defining and then putting a lot more meat about that to describe it a little more.

Again, there ended up being 41 out of those four days, approximately 10 per group. Some had more, some had less.

We had the great fortune to have four outstanding workshop chairs: David Amaral, Geraldine Dawson, Cathy Lord, Daniel Geschwind. They are part of the workgroup, which we will talk about as well, but this group of chairs was incredible. They worked extremely hard. They were generous, they were respectful, they were very inclusive, and we want to thank them and all the workshop participants for their hard work.

We had a nomination process for trying to select participants. The nominations for people to be on these workshops were solicited from IACC members themselves. We also asked the workgroup, which I will name in a little while, but the workgroup itself was asked to provide. That is their job, to provide some help in moving this process forward. We also asked the program staff at the various NIH institutes and the CDC who work with investigators all the time.

Then the workgroup reviewed the nominees and tried to really look carefully at balance. We wanted to have as diverse scientific representation as possible, and we also really made sure to have some public participation as well because that, again, is an important part of this plan to have stakeholder involvement. We ended up having about 60 participants and maybe about 20 observers.

This is the lay version. We were asked by the Committee last time to flesh out the workshop domains a little bit more. This is the lay version we used in the RFI and workshops to describe what was in biology. Again, they could stretch it to include other things. I think it could certainly include things outside of autism formally but inform autism research. This is what was used as an operating definition for this workshop.

Here is a roster of the workshop. I'm not going to go into the backgrounds and credentials of every person. Needless to say, this is a stellar group of people. We had people from all parts of the U.S. We had a couple investigators actually come from England for this particular one. We had somebody who is an individual on the spectrum in this workshop. We had parents. We had just tremendous, tremendous input, and this was a wonderful first start to us, the first workshop we had.

This is the Treatment Workshop definition. Very specifically in the third bullet we said this area includes research studies that evaluate the effectiveness of treatments in real world settings, disparities in ASD treatment among specific subpopulations, practice patterns in ASD programs and services, and their cost effectiveness. We very much wanted to make sure that people understood that services was intended to be included in this workshop.

This was the largest workshop group, and it was really the most diverse. When we started off that day I think we were a little bit worried that we wouldn't be able to get it together, but this group did an amazing job of pulling together. We had practicing child psychiatrists. We had a physician who was from the Defeat Autism Now framework. We had psychopharmacologists and people in educational settings. We had an incredible variety of people in this workshop, and we got a lot from them.

The next group is Diagnosis. This is, again, an area that is pretty important in terms of just trying to define what do we mean by something that is an autism spectrum disorder. I think that we also envisioned that this workshop would also deal with the public health impact, how much are we finding this problem in our communities and how do we diagnose it in communities.

This was the workshop led by Cathy Lord, again with wonderful people.

The other thing I wanted to say was that IACC members were also invited to participate on these workshops, and many did. I think that is an important part of how they understood what was going on. We, again, just very much thank the participants.

Risk Factors, again, was our last workshop, and then this has to do a lot with really looking at what could be behind the etiology of ASD, including genetic studies and environmental studies and their interaction.

This is the roster. Dan Geschwind led us here. We had some great discussions. This was a very interesting group. They ended up doing a lot of work, actually, looking at epidemiologic studies and looking at etiology, which was a very, very strong focus of this Risk Factor workshop.

I'm going to move on to the workgroup. Again, I have been talking about the Strategic Planning Workgroup. These are the names of the people who were on the workgroup. Dr. Insel was the chair. The asterisked names are the names of the people who were chairs of the various workshops: David Amaral, Jerry Dawson, Dan Geschwind, and Cathy Lord. They could carry over what happened in the workshops to this workgroup.

We also had a representative from Autism Speaks, Peter Bell, and Jerry Fischbach from the Simons Foundation. We wanted to have people on this workgroup who really work with substantial autism research portfolios because they understand what is currently being funded and maybe the direction of where they would like to be going. Ann Wagner of NIH ACC was there, as well as Ed Trevathan. These were people who really understood what was currently being funded and where these research initiatives might fall in terms of their portfolio.

We also included a couple people with special expertise: Craig Newschaffer, who really has a good handle on environment and epidemiologic issues, and Denise Resnick, who has a lot of expertise in strategic planning.

This was a workgroup that Dr. Insel put together. It helped us do a lot of this work.

We did have a workgroup meeting about three weeks ago. At that time the agenda was basically this. The group discussed the 41 initiatives. Now, there had been no time after these individual days to actually look across all those 41 together and get a sense of how to piece it together and think about the entirety of what the ideas were, getting the landscape.

This was the first chance to take a crack at that. There was some discussion about really where these things fell, how they fit together, what might be missing, and so forth. That was a great discussion.

It also was an opportunity for this workgroup to begin to formulate some guiding principles or values, things that I think you are going to take forward today that the Committee will have to think more specifically about. What are the things that really inform this plan and what do we mean when we say we are going to do a strategic plan.

By that, we also needed to figure out a framework, so I'm going to spend the rest of my talk really talking about the framework which began to emerge from that workgroup meeting three weeks ago.

I'm going to spend a little bit of time on this slide because I think this is an important place to think about where we are headed. I don't know if people were at the meeting in November other than the Committee, but you may recall that we were honored to have Secretary Leavitt at that meeting to kick us off.

We also had Dr. Zerhouni come to the meeting. One of the things he talked about was a story about how to fill a vessel that was previously filled with large rocks and pebbles and sand. He clearly said the best strategy is to put the rocks in first and then fill around them. He really directed this group to think about what are those large rocks.

We hadn't really had that discussion. We weren't talking about rocks when we were having our little team meetings. I think what shook out, actually, from the workgroup meeting, prompted by a discussion that I think Alison Singer started about questions that people ask, [was that] the group really started liking the idea of posing questions that are, as I say, in the minds and on the lips of parents and individuals and people who are interacting with ASD every day.

I'm a parent myself, so these questions have relevance. We have some other people on our team who are parents. We got together and really thought about how to refine these questions for this group. Again, this is a working model, but I think these questions are pretty relevant.

So, "When should I be concerned about my child's development?" is the first question. The (7) means there were seven of the 41 initiatives that fell into this bin.

The next question was "How can I understand what is happening to my child?" Nine in that bin.

"Why did this happen?" Seven there.

"Which treatments will help my child?" There were nine in that bin.

"Where can I turn for services?" There were four.

And, "What does the future hold?" Again, four there.

Another thing that I liked about this frame work is when you are trying to teach a child who doesn't speak how to begin to speak, a lot of what you work on are the "w-h" questions, and these are essentially most of the "w-h" questions.

Beginning with this, I think that what we are thinking about here is that maybe these questions should really define the large rocks for the plan. This has to be consumer-focused. This has to be a plan that people in the public understand. It has to have relevance to the questions they have in their minds and how they think about this.

Again, to start with this question, "When should I be concerned with my child's development?" because sometimes you are not sure. Sometimes it is obvious but you still don't know if it fits with something. Sometimes it is subtle and people normalize it. I think it is important to know.

So some subquestions under this might be a way to walk this over, then, to the research. So, "When should I be concerned?" and so what are the early warning signs that something might be going on; are there typical characteristics that are part of an ASD diagnostic; how much variation is there in symptoms and severity associated with ASD. Again, that gets to a level of specificity under this overarching question.

Then, what happened, pretty naturally, was that these titles here of some of the initiatives that came out of the research workshops fit nicely under that. I'm not going to read these, but you can see there are lots of different, great questions that fit under this question of "When should I be concerned about my child's development?"

Again, this I think might help make research seem relevant to these questions. I think that is an important part of what we as scientists need to do, is to really draw those lines and make those connections.

Again, this is the second slide in this domain of the first question, "When should I be concerned about my child's development?"

The next question has to do with "How can I understand what is happening to my child?" Under this one we thought about some questions about what could be happening early in development because something is going on, we know, before the age of three certainly, but well before that. Are there known biological differences that help define ASD, and are there subgroups of people with ASD that have been identified that have relevance and can help us with understanding more about it.

Again, here are some of the initiatives that came out from the workshops: looking at infants before age three, looking at neuroplasticity, gender differences, and immune factors. These are all important research questions that really lie under this question of "How can I understand what is happening?" Post-mortem brain and tissue acquisition, biomarkers, phenotyping, and so forth.

We think it is incredibly important to make sure that, again, these questions have relevance to the public.

Our third question is "Why did this happen?" I know that we are not supposed to ask "Why?" questions because they are really hard to answer, but I think those are questions that people ask. So the "Why did this happen?" is basically, is there something in my personal or family history that poses a risk for ASD; how might genetics and/or the environment influence the occurrence of ASD; and do we know how to detect possible causes. So again, there is something here.

Here are a number of research questions that fall under this category, including looking at risk factor studies in special populations, looking early in preconception, looking at the interplay of genetic and environmental factors, and so forth. Again, we really have a lot of questions that fell into this.

Again, here we go with the treatments. So, "What treatments will help my child?" The subquestions here might be things like when do I start treatments or interventions; what do we know makes a difference for those with ASD; what are some of the medical or mental health issues that I need to know about; and how do I know that treatments are both safe and effective.

The safety issue is sometimes overlooked. We have talked a lot about efficacy and effectiveness, but we have to think about safety as well.

Here are some of the interventions and treatments that people have talked about. The services ones were separated out from here. We have a separate category for that because there were some great ideas and we didn't want to mix it up at this point. But, we wanted to look at treatments for older children and we really wanted to look at comprehensive models across ages and so forth.

What kinds of things might predict treatment outcomes. This is the second slide. Looking at novel treatments that are specific to ASD, and then the issues of comorbidity, medical problems, and other things that individuals with ASD might have at a higher rate than the general population. Again, looking at basic cell and animal models that might help really develop these sorts of treatments.

The question of "Where can I turn for services?" we thought about as being what types of services should I seek and where should I seek them; what is my state or local government doing to provide services for ASD. Perhaps we should add the feds in here now, too. What is the cost of treatment and how will it be paid. These are questions I can say that I think a lot of parents are thinking about and are dealing with on a day-to-day basis.

Here is a slide showing some of the ideas that came out of the workshops that I think would address some of these needs and are important to think about. Again, some of the ideas that Ellen talked about: State of the States, dissemination to the community, and cost outcomes.

Our last question really is one of hope but also of being informed. This is, "What does the future hold?" I know a lot of people ask these questions: what will my child be like when he or she gets older; how can I plan for when my child is a teenager or adult; and how can society support individuals with ASD.

Again, this is our last question and this is the last set here of research initiatives. I would hope that these initiatives might provide some of the pebbles that go around these foundational questions that I think are important to relate the plan to the public.

I would appreciate some feedback about this idea, but I would say in my last slide that we have some need for direction from this Committee. Our team has been working hard, but we do need to get to a point where we have a better sense of what you need us to do next. We are ready and willing to work, but we need to know where to go. Our work is not finished. I say that our discussion about the process from here will be important, and I hope you really spend some significant time making some decisions to help us know what to do next.

I wanted to say there is an IACC website and that we are in the process of updating it to include a lot of this information I'm presenting here today so that the public will have a better idea and follow our progress. The Services Report that Lee talked about is also on our website, so please know that you can download that from there.

I guess, just wanting to get our teeth into this a little bit, the team wants to know from the Committee whether or not we would be permitted to begin to do some writing. We would like to begin to write some of the introductory sections of a plan that are kind of boilerplate.

We also need to get going on another responsibility of the Committee, which is a summary of ASD research advances which is outlined in the Combatting Autism Act as a responsibility. We would be working on helping with that.

With that, I'm done. I would be willing to answer questions.

DR. INSEL: Thank you, Joyce. That is really a great summary, and there is a lot to discuss. In terms of next steps, I'm very conscious that I promised everyone a break at 10:30, and we are at 10:30. What I'm going to suggest is we take I'm going to say 10 minutes, which I know will mean 15, to take a break at this point and come back and discuss this presentation. We will talk a little bit more, too, about some of the general issues related to the plan.

[Break.]

DR. INSEL: We wanted to have a chance to discuss what Joyce had presented, remembering that what this is, is really a progress report. In a sense, this is a chance for a mid-course correction as well. But as she said in her last comments, what she is really looking for from the IACC is some direction about next steps.

We will have two subsequent discussions, one about what I will call the Values discussion, which I will lead in a few minutes, and another one which will be led by Steve Foote later to talk about very specifically the next steps and where we want to go from here.

The discussion for right now is to think back about where we have come from, what we have collected so far, this framework that she has laid out as a way of approaching the plan -- let's go ahead and put the framework back up. Thank you -- and your overall sense about this process up until now, recognizing that what we have done thus far is what we agreed to November 30th. It is now done to that point. Going forward, it is an entirely new discussion about what we should do from here.

But we want to make sure that you are clear about what has been accomplished and we get a sense from you about that piece of it, anyway. So, comments?

DR. BATTEY: To what extent do you plan to do a portfolio analysis to attempt to capture all of the ongoing activities that might be addressing some of the issues raised by the strategic plan, both at NIH and elsewhere?

DR. INSEL: Joyce, do you want to respond to that? This is the question about portfolio analysis NIH and elsewhere.

DR. WAGNER: We have been working hard on that, actually, at NIH. CDC and the Department of Defense are also going to help. We have developed a coding scheme to look at the content of what we have now. It is close to being finished. We are doing quality control at this point. We will be able to report on an analysis of the content and the percentage of our efforts that are going into the different areas.

DR. BATTEY: Because in other areas, when you finally figure out what is actually going on and you coordinate those folks, you can sometimes make their efforts that are already being supported more productive.

DR. INSEL: This is a really important issue. It is a little crazy to think about trying to put together a strategic plan before you actually know what it is you are doing currently.

We thought that one way to deal with this would be to take the four categories, the four themes that the workshops were held on, and maybe add one around capacity or infrastructure or something that doesn't fit necessarily into one of those four, like training, and then to at least get a sense of projects and budgets across the current agencies.

Now, part of that as well has been to get some of that information from the private foundations. We heard at the very first meeting from both Autism Speaks and the Simons Foundation about what their current commitments were. They are very substantial. They are actually larger than almost any of the NIH institutes in terms of what they are doing in '07 and '08. Getting that into this same matrix will be very important.

Our hope is that we will have at least the NIH piece finished by the end of March. It is really almost there now. It just needs to be cleaned up slightly. We have the list from Cathy at CDC, but we still need to put dollars associated with that, and the DOD numbers should be coming I would think certainly before the end of March. It is a small amount of money.

What we have from Autism Speaks is the portfolio. I can't remember, actually, whether there are dollars with that or not. I don't think so in this iteration. We don't yet have anything from the Simons Foundation.

DR. ALEXANDER: I had nothing to do with this, so I think I can comment on it. I really like this framework approach the way you have laid it out in terms of the questions that a parent might ask about their children. I really think that emphasizes the fact that this is not just a report for the scientific community but also a report for the parent and patient communities, the subject community.

The only risk of it is that it doesn't incorporate directly people with autism and the older individuals with autism. I think we need to do something about that.

[Applause.]

DR. ALEXANDER: Other than that, I really like this approach of doing it in the context of these kinds of questions that people have on their minds.

DR. CHUNG: I would invite the Committee --

Stephen, you are included -- to help us refine these further. These were just our first attempt at trying to put this together for this meeting. I think that is a flaw here. I think we were trying to just think about when you first begin to ask these questions, but of course the questions never really stop, do they.

DR. SHORE: No, no. Some areas that come to mind include community access to services for adults. We spend 70 to 80 percent of our lives as adults. What about medications? Which ones seem to be most helpful? Then there are parts of the society or community where there is an amount of anecdotal evidence. We have people who are undiagnosed with autism in the judicial system and who are homeless. How many people are institutions that are undiagnosed.

All of this goes into the cost of not providing proper early intervention. So we need to take a look at these things, too. It is a big job.

DR. INSEL: Lee.

MR. GROSSMAN: I'm going to put my two cents in here in terms of how we should look at prioritizing this because it is a huge task. There are always going to be questions and concerns asked from the community of the strategic plan's relevance.

With that in mind, I would strongly advocate that we prioritize this framework with the highest priorities, Nos. 4 and 5, and then have everything else fall off. That way we will be addressing, again, the needs of today. We will be making it relevant.

I think that some of the information that would come out of those priorities also would feed very, very nicely into the other ongoing research projects.

MS. REDWOOD: Tom, I also just wanted to comment that I feel a little lost here in that I think that we have filled in the middle part of the strategic plan but we haven't really talked much about what our overall mission is, and our goals and objectives. I think, as Dr. Battey pointed out, we really have missed not having this comprehensive analysis of what we are funding now. What answers do we have now and what answers do we need next to really help children.

I think we have this wonderful list of ideas, but I just don't really see that we started off the process with having some acceptance as to what our real goals and missions were. I would like to see some discussion around that as well.

DR. INSEL: That is actually the next item on the agenda. It is something that I felt as well was missing from our first meeting. We jumped to step two before we had done step one. I think that is part of what has hung us up in trying to get the strategic plan to where we want it to be. We haven't had this initial conversation about what is this for, anyway.

You said the second thing as well, which is trying to do this without a clear picture of what we are currently funding, what the landscape is now, and how many of these things are actually being done or have been done. I don't think any of these questions have been fully answered, but it will be really interesting to take the current funded projects and look at how they map out onto this framework.

While I would have thought it might have been better to have the landscape of what we are currently funding in front of us before we did this, in a certain way it was actually, maybe, better to just leave that off the table and just bring a group of people together, or now four groups of people together, to say what do we really need here. What are the most important questions.

Now we can go back and say, so how does this map onto what we have done and are we actually pretty well aligned with what people tell us we most need to know. Or, have we missed the boat. Do we need to make a change in the work that we are funding to make sure that we address these better than we have in the past. That can be one of the best ways of using a strategic plan, to refine what you do going forward. Peg.

DR. GIANNINI: Returning to the initiatives, do you think it would be valuable to include some initiatives around parents and families to complete the circle? We have included the adults and the life span. I think the families and parents have such a significant role.

DR. INSEL: So, is there anything like that currently as you look through these initiatives? There are 41. I don't recall whether there is anything that specifically talks about care givers, family members. Joyce may be closer to this.

DR. CHUNG: I think maybe the closest would be some of the things that have to do with comprehensive intervention models. I think the discussions in those groups, those of you who were in the Treatment workshop, were to really think about care givers and really much more broadly than just the individual.

MR. GROSSMAN: Yes. The comprehensive planning involved family matters as well and addressing the family issues and those dynamics.

DR. INSEL: One of the things that kept coming up in each of the workshops, at least the ones I sat in on, was this focus on adults as a huge gap area that we needed to get clear about. We didn't hear as much about the issue of care givers, but it may be that we didn't have the right people around the table to bring that forward.

I think it is a great piece to add in here as we look at going forward. Jeff.

DR. BUCK: I guess I just had a question. I wasn't clear what the relationship of the development of the strategic plan was to the previous roadmap that had been created.

DR. INSEL: By "roadmap," you mean the --

DR. BUCK: This document.

DR. INSEL: Right. That document was developed in the previous IACC as an approach to services, not with respect to research. This effort is really the effort that says what is the science that we need, what are the discoveries we need that will change services in the next generation that we want to be able to implement.

DR. BUCK: I was going to suggest that I thought there was a good section in this roadmap that dealt with issues around financing. Relevant research should be done to learn about issues of payment policies and criteria that, for example, Medicaid, Medicare, and private insurance all use when they determine which specific services they are going to reimburse from which specific providers. I don't see that covered in this.

DR. INSEL: There are two initiatives that dealt with that. One is on the cost outcomes studies and the other was to evaluate models of effective dissemination of evidence-based practices in the community.

DR. BUCK: Neither of those things address what I'm thinking of. That is fine. It is up to the

Committee to decide what it is going to do and what it doesn't do. But we have other examples where there are in fact good demonstrations of cost benefits and so on. Just merely demonstrating the worthwhileness of a service does not in any way guarantee that it is going to be covered or that payment policies are going to give incentives for providers to provide those services.

DR. INSEL: Yes. This is really an interesting area. We talked about this a little bit at the first IACC meeting. There is always a tension between the need to do much better at disseminating [what we have now] and to make sure that the access is there, the financing is there, the capacity is in place, versus the discovery science of trying to create the next generation.

I often remark to people that this was actually a discussion that was really front and center in about 1953, during the polio epidemic. There was a part of the community that said we just need to get better iron lungs to as many people as possible, to figure out how to pay for them. That was really an important, urgent need. But there was also another group that said, can we do something else and should we invest on really taking polio off the map. What they did was both.

We need to keep a diverse effort here, but I don't want to lose the discovery end.

DR. LAWLER: I also very much like this new framework. My question is, given that we adopt this, it is easy to see how many of those initiative ideas will fit nicely under this new framework, but what are some models for how we can incorporate things that didn't come up in those workshops that are prompted when you do consider this.

I think one, the "Why did this happen?", there is a whole missing piece about research about how affected communities perceive genetic and environmental risk factors, how evidence from risk factor studies is disseminated. We need to be in a proactive mode rather than a reactive mode.

I think initiatives could have been suggested had we had this framework, but they weren't. So now, how can we think about going back and filling in some of the gaps that present themselves when you view it in this way.

DR. INSEL: That is exactly the conversation I think we need to have. We imposed this at the end of having the 41 to sort of organize them. All of a sudden, you start to look at this and you say, whoa, we had really smart people in these workshops who are really good at what they do, but we didn't really ask these questions while they were in the room. Maybe we would have gotten different initiatives or different answers if we had.

I'm not sure that the group of us around the table are going to come up with all those missing pieces, but the reason this is coming back to you now is because we thought we need to step back from this -- this is kind of the mid-course correction -- and say maybe there is something else here that we want to bring into the conversation that we want to have on the list. The question was how to do that.

We don't want to go back and have another set of four [workshop.] Well, we might want to have four more workshops, but Joyce would kill me if we recommended that.

[Laughter.]

DR. INSEL: So, how do we do this going

forward. How do we fill out this program. Ellen.

MS. BLACKWELL: I just wanted to revisit your question about care-giving initiatives for a second. We are doing a lot of work on care-giver initiatives at CMS. I wouldn't want us to duplicate any efforts that are already happening there because there may be some special factors associated for families that have an individual with autism.

But we are embarking on an effort. Caring for an individual with a particular disability presents a lot of different problems, so that is something we may be able to help the Committee with.

MS. REDWOOD: Tom, another area I see missing on there is "How do I prevent this from happening?" I see where it starts from the assumption that the child has autism, and there is not much there to how do I prevent autism from happening to begin with.

DR. CHUNG: Actually, I don't know if you recall in the workgroup meeting. There was an initial question about that, but everything in that bin had already been covered in the other one. It circles back to some questions about etiology and biology. Inherent in there are some issues of prevention questions, but I didn't think it had its own integrity, at least from the way it duplicated.

What we tried to do here was make sure that things just fell into one bin. We didn't double count.

MS. REDWOOD: I know as a parent when you have a child and you are considering having another, that is the first question on your mind.

DR. INSEL: Yes. I wonder if there is a way to reword these, or reword one of these, or maybe add an additional item to capture that. There was definitely a discussion about that in the workshop. It certainly is of great interest to anyone who is in this situation. Alison.

MS. SINGER: I just wanted to say I think Lyn is raising a really important point. I think it should be included if only for the fact that it is a very important question that parents ask. By including it in the framework, it is elevating it. It is recognizing that that is a very important question to be studied. Even if we don't have initiatives right now from the four workgroups, I think that may be, as Lyn was saying, an area of need or an area where we need to fill in because we don't have enough studies yet in the 41.

DR. INSEL: What you are telling us is that that is a boulder or at least a rock, in Joyce's terms.

MS. REDWOOD: I think so. I think if we are talking about treatment we should also talk just as strongly about prevention. Then we won't have to deal with the adult services. It is sort of like the iron lung or do we work on curing the disease.

DR. INSEL: Duane.

DR. ALEXANDER: I think this is an important point. It could be incorporated by adding to "Why did this happen?", No. 3. "And, what can I do to keep it from happening again?", something like that.

DR. INSEL: Other thoughts about the framework, basic questions, this approach?

DR. JANVIER: I have a few thoughts. [I am not] a researcher or a biochemist or anything like that but being in the trenches every week, identifying more two-year-olds with autism, and I deal with the families that are asking me that same question. Is this child I'm pregnant with going to have autism. I think that it is like the elephant in the room here.

Again, I apologize; I don't read every scientific journal published. I really think that the new science of genetic has taken on a lot of funding, but I really don't feel that we know what the cause of this epidemic, if you will, is. How can we prevent something if we don't know what is causing it.

Again, we have people here from -- I don't even know the acronyms of all these different agencies, but the environmental sector let's say, from New Jersey. I know there has been a study in New Jersey. The off-the-cuff information I have is they didn't find anything.

I sat in on the Diagnosis group. I didn't hear anybody thinking out of the box necessarily. If I'm a geneticist and I think my gene could contribute to autism, I'm going to try to get money from a foundation that has a lot of money to say autism is the disease of the week, let's go with that.

I do feel strongly that we really don't know. I don't know if there are clues from GI or from different toxins or whatever. Where I work and the families that I work [with], I don't see the clues. I think the reason we have so much genetics research is because we have many families that said "I have two kids in my family with autism," "I have three kids in my family." People said, oh, it has to be genetic.

It is more than that, and I don't really think we know what it is. I don't know if the CDC's database has clues. I don't know if the environmental studies that have been funded in California and New Jersey have clues. I have never heard any of that surface and bubble up to be thrown on the table. I would like to hear that if there is some inkling. I just think we are missing the elephant in the room here.

DR. INSEL: Yvette, would that change any of the way you would approach this? Are you comfortable with this?

DR. JANVIER: I like this very much, also. I think this is great. I think the question is "Why did this happen?" If I knew the cause, I would know why it happened. It would explain to me what risk another child would have. But because we don't know, we are spinning off that, oh, it is like a congenital cardiac condition with a 6 to 8 percent recurrence rate. I don't know if that reassures parents or not.

DR. INSEL: As I remember it, I think Alison was the one who suggested this. The first question was, "What is this?", which is kind of what you are asking. I wasn't sure that that is what we wanted to lead off with, but maybe you are right. We probably ought to start with what is the most fundamental question, what are we talking about here.

MS. BLACKWELL: I have a comment. We talk a lot about quality at CMS. I'm wondering if we are not missing how can I maximize the family member's quality of life. Maybe that is part of what does the future hold, but I think quality is really important.

[Applause.]

DR. INSEL: Alison, you were the one, I think, who put this on there. It was, "What can I expect?" Yes, okay. There was a lot of interest in talking about across the life span what can we expect and how can we both predict and optimize. I think that is in there. But, what the science would be is going to be a lot of work. We have to think very carefully about that.

It is interesting because this is not the way these things are normally done. It is not the way we did it. We backed into this by asking people, tell us about the biology, what are the big questions, tell us about therapeutics. It wasn't until we had this list of 41 and we tried to organize them that we had an organizing principle emerge based on what families would want to know.

Any other comments or issues about this? We will come back to thinking about next steps because this is not a strategic plan. This is a framework. We have a lot of work to do to get from this point to having what we originally talked about of what we want, which is a plan that is accountable and specific and has what the Combatting Autism Act was asking for.

We are not there by any means, but we wanted to make sure you were comfortable with this point in this process. Steve Foote will lead a discussion later about where we go from here and how do we get from this point to where we know we need to be.

If there are no other comment about this, let me open up this next discussion, which really just jumps off from what Lyn was talking about a moment ago. If you could put up the slides, that would be great.

[PowerPoint presentation.]

DR. INSEL: This is a discussion that we really probably should have had at the first meeting. As I was on my way home from [the first meeting], I was thinking about what we had talked about, and I began to realize that even though I have always thought of the autism community as being very diverse, I don't think I had ever recognized just how diverse, based on the comments we had from the public after the meeting, or at the end of the meeting, as well as comments from around the table here.

Remember, much of the discussion at the first meeting was research versus services, services research versus other kinds of research. Some of the comments afterwards were about Lyn's question: What is autism, anyway?

I went home thinking there are people who are looking at this from such different points of view. You have some who would see this as a disease of synapses. Some see it as a developmental brain disorder, some as primarily a cognitive behavioral disorder, some as a disorder of other systems like of the large intestine. Then there are some who wouldn't see this as a disorder at all and are really offended by any discussion in which autism is called a disorder.

This is complicated, and it is not going to be that easy for any of us to talk about this unless we can find some common ground, unless we can figure out what it is that we can all agree needs to be in the bull's eye of what we are trying to do with the strategic plan and with the IACC.

I'm afraid if we don't get some real sense of what we are talking about we are going to end up talking past each other and occasionally shooting at each other without realizing that we are talking about different things.

I wanted to take a little bit of time for us to do, actually, just what Lyn was suggesting, which is to think about what is our mission here. What are we trying to accomplish. I thought one way to introduce that was to suggest to you a set of values that I thought might guide how we talk about autism.

Let me just say these came out of other conversations we have had with members of the Committee over time as we talk to people about how we can make this work for everybody's needs.

Maybe before we get into that I should just make one other comment as a way of providing the context. We frequently do exercises like this where we bring people from many different sectors together to talk about something that we want to do within government funds or within the public arena to try to accomplish something exciting and ambitious.

My comment that I usually make at the beginning of such meetings is that we all come to these discussions with different backgrounds and representing different communities, often.

What I like to ask people to do when they come to this place is to say, I want you to take off the small hat and put on the big hat. The big hat is the hat that, really, you are not only representing a constituency but you are representing everybody's kids.

While you are here, you are a public servant. Actually, you really are a public servant because you are a special government employee for the day. Not that you get paid that much to do this, but that technically is what your status is.

What that means is that, as a public servant, you are serving the whole public in some way. Though you come informed by what you know and you come with an interest in serving the people who you know best, it is also important that you are open and that you are thinking beyond your own constituency so that you can represent kids everywhere and adults everywhere who are struggling with this.

We tend to forget that because there is a sense that you come to this IACC with an opportunity to lobby or represent the people who you feel are looking to you for leadership. That is understandable. It is a little bit like, I guess, for people down the street a little bit who come to Congress knowing that they represent someone in Wisconsin but they also represent a much larger part of the American pie. They have to think about how the decisions they make and policies that they are trying to create affect everybody.

Let me just mention that this is a "big hat" conversation in terms of context. I hope we can all embark on it in that way.

Diane, let's just look at the first couple of slides here, then. These are the issues around values that I have heard from people on the Committee and I thought would be worth sharing to see whether we can all at least buy into this approach to what we have to do here.

One is this sense of urgency. We have already heard this today. I think Lee mentioned it, as well as others. These are problems that are continuing to grow, huge expense, huge social consequences, huge emotional consequences, and we need to do something about them in the short term.

Collaboration. This is really asking for your big-hat behavior. Treating others with respect, opening up to diverse views, and making this a very open discussion. I think some of the best information will come from the tension between opposing opinions. That is just fine. It is not that we need to agree. But we do need to create an environment in which people are comfortable disagreeing.

This consumer-focused piece I think you just saw a great example of in taking what we had in the plan that was coming largely from the scientific community, but not entirely, and then redrafting it so that it had information that was useful to families in a much more immediate way.

The next slide is on excellence. This is on the research side in particular. Keeping the bar very high. This is not easy to do often. In some ways, this runs in the face of the sense of urgency. You want to get information quickly, but we have to also make sure that the information meets the highest scientific rigor and that we look at what is both necessary and sufficient when we ask about whether treatments work or whether the biology holds up.

Partnerships. We got this from the very first IACC meeting. This is one area of biomedical research where, remarkably, it may be the case that the private foundations will be investing more money than the government is investing at some point. We are not quite there yet, but we are not far off from that. It is going to be critical that there is cooperation and sharing and that we are not all just doing the same thing.

One of the greatest concerns here is if all of us are funding the same people to do the same work, rather than spreading out and trying to conquer this through different mechanisms and different approaches.

Finally, we like to talk about the SMART approach, being Specific, Measurable, Achievable, Realistic, and Time-bound research. That is, having all of this built into a system of clear, transparent accountability.

We heard this in the first IACC, that this might have been what was most missing in the strategic plan that we did, the matrix, back in 2003. There were a lot of great ideas in there, but it didn't have the accountability built into it that we needed. From where I sit, the accountability isn't just an issue for NIH or CDC, it is really for the whole community to think about who is going to do what parts of this plan and in what time, and who will be held accountable if it doesn't get done.

I would like to think that as we go into the implementing phase -- we are not there yet, but hopefully we will be there soon -- that we make this a really important part of the discussion and everybody who is around that implementation table takes a piece of this and says I'm in, I'm going to do this, and I'm going to do it by such and such a date. I think that is really what we were missing in the previous generation of this effort.

Those were the six values that we had come up with, mostly from the discussion we have had with many of you. I just thought we needed to lay this out in this case so you would get a sense of what we are hoping will be let's say the guiding principles, if you will, for the plan and for the work we do here together. Comments?

DR. LAWLER: How about efficiency? I'm trying to think of a way to capture leveraging ongoing projects and programs as much as possible so that we don't duplicate but also so that we prioritize real data gaps in a very limited funding environment. I'm not sure if that deserves its own or maybe can be emphasized in one of the other principles.

DR. INSEL: Great. Let's add this in. Anything else? Are people comfortable with this as a set of values going forward? We are not going to make you wear this as a headband or something, but I just feel we need to put it out there. Story?

DR. LANDIS: I think that this is actually a remarkably important thing for us to do not just in this particular arena but in many of the other disease arenas that we work in. I think in Parkinson's, which is one of the NINDS-specific diseases shared with a number of other institutes, oftentimes the foundations have been working at cross purposes to NIH. That is not in anybody's best interest.

These are wonderful values. I also thought that the principles for the initiatives, those focused questions, were things that I would take back to my institute to look at with respect to other diseases for which we are responsible. I think you could actually substitute any number [of conditions.] Why do I have Parkinson's. What lies ahead of me. What does it mean for other members of my family.

I think this group is doing some very interesting and important work not just for this disease but cross-cutting principles across multiple whatever is the politically correct description that is acceptable to everybody with a big hat on for autism spectrum disorders. I heartily endorse both of these efforts.

DR. INSEL: Thank you. Other comments or thoughts?

[No response.]

DR. INSEL: This leads naturally, then, into thinking about the mission and what it is we want to accomplish here. Diane and I made up slides, and then decided not to do more than just to put them up there. Actually, maybe, Diane, it is worth putting up the other set of slides. Steve, go ahead.

DR. SHORE: Also, one thing to think about is looking at working with people that are on the autism spectrum as opposed to just for. Then it becomes more inclusive.

[Applause.]

MS. REDWOOD: I think perhaps that could be captured by defining partnerships more broadly so we are talking about affected families and individuals as well.

DR. INSEL: Good, good. I wonder if that actually would be worth spelling out in some very explicit way. If it did jump out at you, it is not going to jump out at other people.

DR. SHORE: Yes, I think it should be explicit.

DR. INSEL: Good. This goes back to Lyn's original comment. Can we define what the mission is at least for the strategic plan, what it is we are trying to accomplish and why we are doing this anyway. It is going to be difficult to do this as a group of 18, but what we may do is get some thoughts from you.

Maybe it would be helpful to look at some of the mission statements that other people have put together. This is from the Autism Consortium, just for your interest. I thought you might find these interesting to look at.

"Support a disease-based collaboration dedicated to rapidly advancing the understanding, diagnosis" -- you can read it. They have a tag line. I think it is something like "Speed matters" or "Urgency matters," something like that.

The next one is from Autism Speaks. It is much longer.

[Pause to allow participants to read slide.]

DR. INSEL: The next one is from DOD.

[Pause to allow participants to read slide.]

DR. INSEL: Is there one more?

MS. BUCKLEY: Two more. The last one is from SARC.

[Pause to allow participants to read slide.]

DR. INSEL: After you read all these you will probably think we don't need an IACC. Everybody is already doing it.

[Laughter.]

DR. INSEL: But I do think there is value in our agreeing to what it is we are trying to accomplish besides how we are going to do it. To use Joyce's "w-h" words, this will be a "what" question in terms of the mission. I'm open to suggestions that anybody has about what you see as the mission at least initially. If we want to define it as the mission of the strategic plan, there is information in the Combatting Autism Act but it is pretty skeletal. It just says really to guide research with budgetary requirements for the next period of time.

Comments, thoughts? Cathy.

DR. RICE: I think what is unique about this group goes back to the values that you had laid out that we are trying to achieve here. It is unique because we are not one agency or organization trying to have this mission but that we are trying to have this sense of urgency and this spirit of collaboration. I would urge us to look at the values and say how do we put this into our mission statement.

DR. INSEL: You have given us two words already, "urgency" and "cooperation."

DR. RICE: You gave us multiple words, but I think that they definitely characterize what we are trying to do for the outcome. That is what we have been talking all this morning in terms of the focus on research versus provision of services. That is some of the tension still to be resolved, and the challenge of this Committee is to define what is our ultimate outcome. The values define how we hope to get there.

DR. INSEL: Anybody want to take a stab at it? Actually, [as to] the DOD one, I gather from Lyn that they put that together in the course of a few minutes of discussion.

MS. REDWOOD: In about a six-hour day with the help of a facilitator and a lot of white boards.

[Laughter.]

DR. INSEL: I was thinking of the efficiency suggestion of building on what we already know.

Tell me what you think about this. I really believe there is value in our coming to some agreement about what the plan should be doing, but I want to make sure that you see it the same way and how you want to go forward with this. Lee.

DR. SHORE: I think the DOD example respects people with autism. We need to think about what we are doing. There is a lot of talk about prevention and cure. I think what we all want, parents, researchers, people on the spectrum, is to find ways to help people with autism lead fulfilling and productive lives.

That doesn't take away from the fact that there are many things about autism that are disordering. When you have someone with autism that has such sensory issues they can't bear to remain in their skin, we have to do something about that. When you have somebody else who may not have developed a reliable means of communication, we definitely have to do something about that. That is what brings us all here.

If we think about a cure for autism and eliminating autism, there is a lot that people with autism have contributed to society. People with autism, people we suspect may have had autism but we don't know because they are long gone. This is something we need to consider as well.

DR. INSEL: Stephen, as you look at this, does this speak to you as what you would want to see us do here with the strategic plan?

DR. SHORE: It does speak to me.

MS. BLACKWELL: This group was looking particularly at treatment. I might like that mission statement better if the word "treatment" wasn't there because aren't we looking for improved outcomes in general? I'm not sure it is just treatment. I think we go beyond that.

The other things that occurred to me were that we want to try to find a way to maximize resources. Part of that is building on the partnerships that we have here. This is such a unique group. This is the only place where I have had an opportunity to really start building sorts of partnerships with our fellow agencies. A lot is starting to come out of that. DOD doesn't have that in their mission, but those are a couple things that struck me when I read it.

DR. INSEL: That was Cathy's point as well. What we ought to be is somehow pulling all of this together. But I think it is a place to start. Lee and then Gail.

MR. GROSSMAN: I like the DOD's comments. It must have been approved by somebody, being a government entity, so it would facilitate our lives. From a practical standpoint, though, I think whatever mission and vision that we do choose [would] follow more of a corporate model. In a corporate model, since this is the vision and mission for a strategic plan, strategic plans, even though they are long term, are defined by time.

I think, speaking to the urgency matter, that if we can, in our mission and vision, somehow define what we are trying to attempt and a time frame that is specific, that will put the onus on us to act and to achieve that mission and vision.

DR. INSEL: Gail.

DR. HOULE: As a person in a pretty services-oriented position, when I saw the DOD it was obvious to me that that came out of, and in fact it said at the bottom the source was their congressionally mandated medical research program. I think that our mission statement could be much broader than that. It didn't address interventions, services, some of the parent partners, the family partnerships.

In looking at these, I would also look at what type of program is this a mission statement for. DOD has this new congressionally mandated medical research mission. We could also look at the Combatting Autism Act and the IACC and the statute and look what appears to be a broader mission reflected in the mission statement.

DR. INSEL: I guess what you are saying is maybe we need to clarify whether we are talking about a mission statement for the IACC or for the strategic plan. Those could be quite different.

DR. HOULE: Well, yes, they could be quite different. I was reading the statute, and the IACC is a piece of the Combatting Autism Act.

Now I'm confused. Are you talking about the strategic plan only in terms of research?

DR. INSEL: The Combatting Autism Act gives us very clear instructions about developing a research strategic plan. That is what they call it, a strategic plan for ASD research, and they define what they mean by that. So it is partially, anyway.

We have instructions about what that is supposed to look like and that it is supposed to cover a five-year period and that it will be updated every year with reports to Congress. The IACC is much broader than that.

DR. HOULE: Sure. It is just my opinion that your research plan and your legislation, even in your research areas, is broader than the DOD's small, focused program and amount of money and congressional mandate that they got. But that is just my opinion.

DR. INSEL: Absolutely. Even for the research plan it is clear that we are a much broader effort. We only put that up there to get your creative juices flowing a little bit. Lyn.

MS. REDWOOD: Just a comment on that. Since we did have such a small pot of money -- I think it was only $7 million -- we decided to focus specifically on treatment.

Since we are part of the National Institutes of Health, I think health needs to be somehow included in this mission statement. I think we also are about science, so I would say our mission is rapidly advancing our scientific understanding of autism spectrum disorders in an effort to restore health and, as Steve added on, help those on the spectrum lead fulfilling and productive lives. Try to incorporate health and science.

DR. INSEL: I think we should take a vote. That is great. That is a great place to start. Let's get some other ideas about other things people want to have in there. I heard cooperation and other pieces of this, and something about urgency as well.

I'm not expecting that this group will come up with final language, but if we can start with that wordsmith it and add on, then we will have the Autism Team work it over and get it back to you so we can come up with a final statement.

In the best of all possible worlds, we would take six hours and work with a facilitator and get this done, but I'm actually so concerned about moving on with a lot of the other tasks that we have, I would rather get your best ideas here and then we will incorporate and get it all back to you. We can do some of this electronically as well.

Lyn, I feel like you have gotten us [started.] Do you want to write that up there? We may be pretty close with just the comments you provided.

MS. BLACKWELL: We might be able to borrow some language from the Olmstead Act that talks about people with disabilities living in the community or the place where they choose to live. We could certainly forward a lot of the good work that we have done to the team.

DR. INSEL: Sure. That is already out there. Lyn, do you want to read this off again [so] Joyce can put it up?

MS. BUCKLEY: I can type it here, too, if you want.

MS. REDWOOD: For the sense of urgency, which I think we all feel, I had "To rapidly advance our scientific understanding of ASD," that was one of the pieces. Then the reason to do that is to try to restore health and help those on the spectrum live fulfilling and productive lives. There is "scientific" before "understanding."

MS. BUCKLEY: Thank you.

DR. RICE: Lyn, didn't you say fulfilling and productive lives? I think that adding "productive" is a nice addition as well.

MS. REDWOOD: Actually, those were Stephen's. I don't know where he went.

DR. RICE: The only thing I would suggest adding to that, maybe on the end, is "through coordination" or "collaborative public and private partnerships." Just somehow to talk about our collaboration.

MS. SINGER: I might also add "to restore and improve health," so that it is forward-looking and optimistic.

MS. BLACKWELL: I'm not sure we even need the word "restore." I think maybe we could just say "improve health outcomes." "Restore" seems to connote to me that something has been lost. Or, "to maximize health." We should be positive.

DR. INSEL: One thing that is nice about the health outcomes is it covers this broad range of problems that we are hearing about. It is beyond just the narrow definition of what meets the criteria for autism. I think you want to definitely somehow put that in the mission, that we are talking about the whole child, the whole person, the whole adult, whatever, and not just a reduction of specific symptoms, which would be lowering the bar more than we want to.

Other thoughts about this as at least a starting point? We may want to wordsmith it into two sentences. Don't worry about that part. It is more the ideas. Chris.

DR. McKEE: If Dr. Fischbach were here, he would want the excellence or the rigor standard put in there somehow so it doesn't get overlooked.

MS. REDWOOD: I think you might want to change the word "those" to "people."

MS. SINGER: I think you could also, in the second line, replace the "to" with a comma so that it is clear that the advancement of scientific understanding has a broader role, to capture what Dr. Insel was just saying, to capture all of the ideas that have been brought up at the table and not limit them in any way.

MS. BUCKLEY: I'm sorry. I didn't understand what change you wanted.

MS. SINGER: "Rapidly advance our scientific understanding of ASD, improve health outcomes, and help people on the spectrum lead fulfilling and productive lives."

MR. GROSSMAN: I'm not sure what the right word is, additional word or words, but "improve health outcomes" seems too limiting considering there are social, educational, and behavioral outcomes also to consider. Maybe "life span outcomes" instead of "health outcomes"?

MS. BUCKLEY: I'm sorry. I missed that last one.

DR. GIANNINI: Responding to Lee as well, I think it is more than scientific understanding. Maybe "psychosocial" is not the right word, but there is something else that has to be there, and understanding. Someone said something about "well"?

DR. INSEL: Well being.

DR. GIANNINI: It could be wellness.

DR. INSEL: So, "health and well being" instead of just "health outcomes."

DR. GIANNINI: Or "wellness" could be another word. But I'm not wordsmithing here. I'm going to the concept. I think there has to be something more besides "scientific understanding."

DR. MORRISSEY: We obviously would like to see greater acceptance of people with autism in the community. What if we put in "scientific and common understanding." The issue is we want people to be included and to be accepted as contributing members of society by the larger society. We promote that through everything that we do, but to say it in the mission statement I think is very proper.

DR. INSEL: For us it will be helpful to keep collecting these ideas. We are at the point of collecting words and ideas. We will do the wordsmithing, so don't worry so much about that.

Any other thoughts and comments? We have a bunch of things up here.

MS. BLACKWELL: Maybe you could say "productive lives in the community." Maybe that would capture [it.] I agree with you that something about the community needs to be in this mission statement. Maybe we just need to say we are going to improve our understanding of ASD. Maybe that leaves it open enough where we have room.

DR. INSEL: Stephen.

DR. SHORE: There is a comment from Scott here. "Societal understanding" in place of the question mark. "Societal and practical." "Practical."

MS. BUCKLEY: Instead of "societal"?

DR. SHORE: No, no, with. There are three things there now.

MS. SINGER: I think since there is clearly so much interest in doing a mission statement we might want to think about drafting a mission statement specifically for the strategic plan and then a mission statement for the IACC overall that really captures some of the broader issues that may not be encapsulated in the strategic plan itself.

DR. INSEL: This is an important point because the strategic plan does have bounds on it. Actually, the vision is already in the act. It is the mission that we would have to work on to say what the time frame is, which is I think five years, the fact that it is nimble and updated every year.

But it would be different. The IACC can do a lot more than what is in the strategic plan, and I was hoping that as much as we would accomplish for this discussion was just to get something for the strategic plan so we could agree on what that should look like at the end of the day, or at least at the end of Steve Foote's comments later.

Alison, to go back to this, how would you change it if this were going to be, in a more limited way, looking at the strategic plan only?

MS. SINGER: I think we have to really look at the statute and what the statute intended when it specifically indicated writing a strategic plan for research. Then separate those goals from other important goals so that they are not mixed in together. When we talked earlier about the need to really create a parallel process for looking at services, I think we identified a lot of the issues that came up in the treatment workshop and in the discussion at the last IACC meeting and here today.

We want to make sure that services get the attention that is warranted. I think we all agree that services are a very important goal, but I think we also have to be careful that we are focused on the statutory intent when it specifically talks about creating a plan for research.

DR. INSEL: What it says is "to develop and annually update a strategic plan for the conduct of and support for autism spectrum disorder research, including proposed budgetary requirements, and submit to the Congress such strategic plan and any updates to such plan." That is about all the instruction we have been given.

DR. RICE: That sounds like a good factual start but not very inspiring. Maybe we start with how do we translate that more with the inspiring values that we are trying to have but with those facts.

MS. REDWOOD: I agree with Alison. I think it would be more clear if we actually had two, one specifically for the whole entire IACC Committee and then one just for the strategic plan that was a little bit more narrowed and focused.

Tom, you were talking about wearing a big hat. There are families out there who have children that are just absolutely miserable. They don't sleep at night. They have diarrhea. They pull their hair out. They injure themselves. Those families talk about prevention because they want to prevent that from happening to anybody else.

But then you have people on the spectrum that are very high functioning. So, how do you meet the needs for such a diverse community. I just really am at a loss for how to meet the needs of that whole community on this Committee. If anybody has any suggestions to make this broad and inclusive but still have targeted things that we are trying to accomplish.

DR. INSEL: Cathy.

DR. RICE: I think that is a really important point. Lyn, you made a good point about needing to put prevention on the questions. I tend to think of prevention as not prevent the whole person disorder but how do you prevent the disabling symptoms.

I just throw that out as a concept for people to react to. Does that cover the whole range? Here you still have that person and you are trying to get rid of those things that are causing the difficulty: the GI, the hair pulling, the not being able to speak, but not lose the unique qualities that are positive aspects of many people with autism. I would just encourage us to think of prevention in terms of disabling symptoms.

DR. SHORE: I think there is a lot to be said for that.

MS. REDWOOD: Can we somehow incorporate that into what we are trying to accomplish?

DR. INSEL: I think, in fact, the language could do just that. You said it much better than I did. That tension is exactly what I have been worried about. That is why I wanted to have this discussion here. It is so diverse. We have to find a language that covers that diversity and speaks to everybody's needs but still accomplishes what we need for those who are most severely disabled. That is what makes this so difficult to do.

I think that some of the language that is in here actually does that. I think you can put in language about prevention and language about optimizing treatment and language about leading fulfilling and productive lives, and it covers the entire spectrum of the people that we want to be able to address. But we have to find language that everybody can understand in that way.

MR. GROSSMAN: There are groups of us that are working on similar language. Stephen has been involved with developing some of this commonality so that we can all agree on the same things. Like, if we bring up a term such as "recovery," what that means. It has been a very interesting process.

I think, in response to what Lyn was saying, that that is the complexity of what we face. There is such a tremendous diversity.

I come from, in my experience, people that are high functioning, people that are low functioning. It is kind of hard for me to make a judgment call in terms of what their level of suffering and pain is. All I know is that they are all in crisis.

We have taken on the mantle of, instead of trying to address that individually or to be divisive, gathering terminology that the rest of the disability community uses and puts up on their banners, such as "Creating opportunities" and "Maximizing potential." I think that is what we are trying to do for everybody that is on the spectrum and, at the same time, do the same thing for their families, who are equally as affected.

MS. BLACKWELL: This is what always keeps me grounded when I'm trying to think about my goals for my own son. I don't want anything different for him than what I want for my non-disabled child. If you think of it like that, it really starts to make things pretty easy.

What do you want for your family member? Friends, a life in the community, a relationship with the family, to be happy. That always keeps me grounded when I'm thinking about goals for people with autism.

DR. INSEL: Other thoughts about this? We have a lot of good material here. I think if we initially want to focus this down to talk about what the strategic plan will have as its mission, we can probably narrow some of the language a bit.

Would the group be comfortable with the Autism

Team reworking some of this, putting it into a format -- this is short of spending six hours here doing it -- and going back to you in an electronic fashion? It will probably be, at the end of the day, something fairly brief.

I think what we will do as well is to include the value comments into the mission in some way so that you have both these shared principles as well as what the shared goal is. Okay? Are we good with that?

If that is the case, you get a lunch break.

[Laughter.]

DR. INSEL: We will come back after lunch and we will begin the discussion about the next thing. I think we need to be back by one. One-fifteen is what we will do for the lunch break.

[Lunch recess taken at 11:57 a.m.]

AFTERNOON SESSION

[Reconvened 1:18 p.m.]

DR. INSEL: Welcome back from lunch. Welcome to Dr. Steve Foote from the Autism Team who is going to take us into the future. We have been talking about the strategic plan and where we have gotten to so far. We have focused a little bit on the big picture and the values and the mission. Now we want to get to the details of thinking about what will be the next steps given where we are now three months into this and what we want to get accomplished between now and the May meeting.

Steve, I will turn it over to you.

[PowerPoint presentation.]

DR. FOOTE: Great. Thanks, Tom. As Joyce reviewed this morning and as there has already been some discussion, we have completed some early, possibly partial steps toward developing a strategic plan in accord with the process that was adopted by this Committee at their November meeting.

As Tom has indicated, we have decided that it is time to catch our breath, put a little pause in, and get recalibrated with the Committee because this is your strategic plan. We need to listen to what your reactions are to these early steps and we need to elicit from you some guidance as to how to proceed from this point forward.

There are a number of lessons that we have learned during these early stages. I want to allude to some of those lessons and some of those steps and review a little bit of that as things to keep in mind when you get to making decisions about how we are going to proceed from this point forward.

We have a couple of proposed scenarios which are quite different. It will probably take us a little while until we get to that point, but the idea is that when we get to that point of the discussion some of these factors that have to be kept in mind we will have already talked about.

Here is a very quick summary of what Joyce covered this morning in terms of what are the pieces of this process that are currently in play and on the table so that as we attempt to assemble this puzzle you know what some of the existing pieces are. Then you can talk about whether there are other pieces that need to be added in order to make this thing make sense and be able to move forward.

We have the proceedings from the workshops that we held. We have the 41 draft initiatives that we spent some time discussing this morning and that all of you had received previously as Email. We have the way we have now structured those initiatives, or at least grouped them under these proposed questions that would be organizing headings for how we cluster initiatives. We have some feedback from the workgroup that we also discussed today.

We have a number of supporting documents that were developed in anticipation of the strategic plan or that already existed, such as the summary from the Institute of Medicine proceedings, and so on, and the evaluation of the previous autism matrix. We have the process that you all approved in November.

Those are the pieces as they exist right now. One of the questions is, are those all the pieces we need. Do we need some more pieces and do we need some more process.

There are some specific issues that have a number of facets to them that we want to address today and that we need to keep in mind when you are making your decisions about how to move forward. One has to do with IACC oversight and involvement. That is, how much should the Committee be involved and in what ways should they be involved.

When we started out on the early part of this process, the workgroup and the team were delegated a number of responsibilities which then played out over time. The question now is, is the Committee comfortable with that style of proceeding. Do you want to change that; do you want it to be more elaborate. That is one issue.

Another issue is stakeholder participation. As we conducted the workshops and as we formed the workgroup, there was an attempt to incorporate a variety of stakeholders. The question going forward is, what principles do we want to use from this point forward and what kinds of delegation for appointing people to these groups, whatever groups you decide there may be.   What principles should be used in selecting stakeholders to participate in succeeding stages of the process.

I'm going to review those. Then we are going to talk about possible scenarios for next steps. I'm going to be asking you for your input and to make some decisions. Then we are going to discuss the issue of budgetary requirements for the strategic plan.

As you all are aware, the Combatting Autism Act stipulates that there should be budget requirements attached to the strategic plan, but the wording is extremely brief. You need to decide what your interpretation is of what that requirement means. How can we proceed to get to that stage of assigning budgetary requirements to the strategic plan.

Here are some points that I'm going to put out on the table. I will welcome comments at any point as I move through this. There are a lot of question marks in here, and that is deliberate because there are questions to you from the Autism Team about how we can help implement whatever process you decide on.

So, does the approved process that we have in place right now reflect desired balance of oversight from you; delegation of authority to the team, to the chair to appoint people to committees, and so on; your review and your approval. There are a certain set of those instantiated in the current plan, and we need to decide whether that is appropriate or whether it needs to be revised.

One question that will come up, I think, is do we need more IACC meetings. Do our meetings need to be more frequent in order to accomplish this large amount of work that needs to be done and that requires oversight from you. If there is a decision that the IACC needs to be more involved, is it your desire to do that as a committee of the whole or is it your desire to do that by appointing a subcommittee or something like that. When we get to suggestions about specific ways to proceed, we will need to take all of those things into account.

As we carried out the early stages of the strategic plan, we had been delegated to do that with relatively broad instructions. During the course of carrying out our responsibilities, we would from time to time get feedback from one member or another of the IACC or from somebody who was outside the IACC but wishing to inform us of their opinions about things. In the course, then, of doing this, we had to make a lot of decisions about when to move forward, when to check back with the workgroup, when to check back with the Committee as a whole.

Our feeling right now is that we need more detailed guidance from the Committee about exactly when we should go ahead and move forward and when we need to check back with either your designated workgroup or to you as a Committee.

We need to discuss this very general issue of how the IACC fulfills its strategic plan responsibilities, what kinds of meetings you want to have, how often you want to have them, who you are going to delegate responsibilities to, and so on. There are a number of decisions to be made here, and we need your input about these things.

One area in which there were a number of decisions to be made and then we would get feedback about these decisions was the question that has come up a little bit earlier today, which is selecting participants. Every time we have a workshop or every time we designate a workgroup, there are many, many decisions that have to be made about who is going to be a participant in those activities.

The team moved forward with a lot of guidance from the workgroup about how we constituted the workshops and so on. But then, when we get feedback from either an IACC member or somebody else suggesting a change in the process or a different constituency to the group, we are put in the position of either ignoring what that person is telling us or letting that kind of input then influence the process after the Committee as a whole has made some decisions.

That is a tough spot to be in, and it is one that has certain perils in it. Obviously, there are only a certain number of times that you want to be going back and checking with the Committee about the next step and the next step and the next step in this process, but I think it is very important to get input from you and have you make some decisions about how detailed your delegation to us of these kinds of responsibilities should be or to whom the delegation is.

We would like to hear from you some criteria for ensuring diversity and appropriate representation. There has already been some allusion to that this morning. Then the question of are there other venues, other formats, other paradigms for collecting information about the strategic plan and proposed activities under the strategic plan that we should be utilizing. When I say "we," all of us should be utilizing. How open or closed should these various forums be.

Those are the questions and considerations that arose as we undertook this process. Is there discussion about those things or thoughts about those things or responses people had as they watched this play out? A number of you actually participated in some of the workshop and workgroup activities. Are there issues you want to get on the table that we can discuss in a general sense for a while before we undertake this job of trying to make some specific decisions about how to move forward?

MS. BLACKWELL: Steve, there is one thing you didn't mention. I'm in a unique place here today because Lee and I were charged with talking about the Services Subcommittee. I reviewed a lot of materials associated with FACA, the Federal -- help me out here.

DR. FOOTE: Advisory Committee Act.

MS. BLACKWELL: Federal Advisory Committee Act. In fact, I have a whole folder of FACA stuff with me today. You might want to talk to the group a little bit about how the fact that we are convened as a FACA group influences the sorts of decisions that we make about delegating and what we can delegate and what we can't delegate. I think that is part of this discussion. Without that background, I don't know if we can have a really meaningful discussion.

DR. FOOTE: Right. The Committee is an advisory committee. The meaning of that is that you are duly authorized to provide advice to federal officials. So you as a group can get together, reach a consensus, take votes, generate specific documents, and so on that you are then authorized to communicate to federal officials as advice about federal business. There are a detailed set of rules that govern the operation of such a committee.

There are a number of FACA committees. This is part of the reason the law was established. There started to be a proliferation of advisory committees providing all kinds of advice to federal officials. It was determined that there needed to be an orderly set of rules to govern the activities of such groups, that such groups had to meet certain criteria for representativeness on their membership and how they were constituted and how they operate.

There are a whole set of bylaws. The meetings have to be open. There are sunshine laws that apply, and so on.

In terms of the specific issues about delegation of authorities, as was discussed this morning, you are authorized to set up a subcommittee or subcommittees. Subcommittees are to be composed entirely of members of the parent advisory committee. Their activities can be conducted in a number of ways, but the critical point is they are always there to report back to the parent body.

So, you can establish a subcommittee, but the subcommittee then can't take off and run its own show. They have to come back and report to you. Any final say in what your advice is to federal officials is absolute.

You can modify, rewrite, whatever, anything that a subcommittee reports back to you.

You are also authorized to establish workgroups. Once again, the key point is that the workgroups are always reporting back to you.

In the original process, Dr. Insel was authorized to establish a workgroup which then oversaw the activities of the team and oversaw the early stages of the strategic plan process. All of those activities were conducted under your auspices, and all of the workgroup activities have to be reported back to you. Anything that has been done up until this stage is entirely tentative and subject to whatever you decide you want to do about all of those activities: which of these work products you want to use, not use; how you want to prioritize them; and so on.

Workgroups are useful because they can contain people outside of the IACC itself. It is a good way to bring in expertise or other stakeholders. We proposed to you, and you accepted, the workgroup idea because that was a way to incorporate more stakeholders and get broader points of view.

I think those are the basic issues here. There are always rules governing what we do, but those are the basics of it.

Other issues that people want to discuss about stakeholders, delegation, proceedings, anything?

DR. INSEL: A comment from Cathy.

DR. FOOTE: Yes, Cathy.

DR. RICE: I just have a clarification question. From what is on the board, it seems like the first decision is, is the Committee pleased enough with the 41 objectives that the vote we are deciding on is that those go forward to become part of the strategic plan, or is the question if the Committee is not happy with those 41 objectives how do we move forward from there? Is that the gist of what you are asking?

DR. INSEL: If I can just clarify, we are really still at the process stage. I wouldn't worry about whether it will be 41 or 21 or 61. It is really a question of how does the Committee want to get from where we are to where we are going to end up. Do we want to follow basically what we have been doing or do we want to shift the process in some way.

DR. FOOTE: When I said there were pieces on the table, I really meant that literally. There are 41 initiatives currently sitting on the table for the Committee to do with as it wishes. They may decide that there are areas of science that were underrepresented in the workshops as we conducted them and that there needs to be some implementation of another workshop, a larger forum, whatever it is, a way to collect additional ideas.

It is just a piece that is sitting there on the table right now. The question is a very basic one. We are not asking the Committee to adopt those 41 or something like that. That would be premature. We are not asking the Committee to prioritize those 41. That would be premature at this point. I think we need to have a more basic discussion about whether we have generated the right things to play with.

DR. INSEL: Just one more thing to add. You told us already this morning that you felt that before we could go forward any further you wanted to look at what was currently in the portfolio so you would have some idea of what we are currently doing.

In a way Steve is asking, how would you want to do that. We can get the numbers, but who would look at them and how will you want to use that. This is really about a process.

DR. FOOTE: Right. Exactly.

DR. INSEL: Pat.

DR. MORRISSEY: I guess my question is related to what you said, Tom. I think that is a daunting idea [for] those of us, for example, who have no expertise on basic research, even if it is summarized, [to think about] where it fits or how it matches up with the things that were generated in the 41.

I would like to propose that somebody take a look at your summary and organize that summary in terms of those questions, maybe as a chart where you have the stuff in the 41 over here and the stuff from whatever you summarized over here. People who have expertise in different aspects of that can comment on those pieces.

I think you have to do something that basic because otherwise, given your interest in moving forward, if you just sent us all a summary and said, "God bless you all," I don't think you would get an answer in a way that you could use it to respond to what we are asking you to do.

DR. INSEL: I think what Steve is asking us is, you are saying somebody should do this but who is the somebody and how will we figure that out.

Lee, did you have a comment?

MR. GROSSMAN: I'm not really sure of the process on how we should move forward, but there was a lot of work that was done, so we have to give fair consideration to the 41 topics that are now before us.

Somehow, though, I would hope that in this process, and I know it needs time, but we really do need to have some additional public comment on those 41 to see if that does resonate with the public, if that is what they want. There might be some very interesting feedback and some worthwhile feedback that comes out of that.

Again, I'm not proposing any type of a format to do that because I don't know how to best achieve that, but town hall meetings would be great. Again, I don't want to in any way here try to recommend how we would go about that, but I think it is very important to solicit that.

DR. INSEL: What does "public comment" mean?

Is that an RFI or is it town hall meetings or webinars? How would that be done?

MR. GROSSMAN: Yes.

[Laughter.]

DR. FOOTE: I think that it is okay to leave it at this level of non-specificity right now because when we move into possible scenarios, that is when we need to start making these kinds of decisions. I think the general point [that] there ought to be more public input is the level of discussion we are at now.

MS. REDWOOD: I would also like to see more IACC input on the process than there was. I think the process was laid out very nicely at the first meeting, but one of the things that was lacking was input in terms of who was going to populate some of those committees. I'm concerned that we missed a lot of very significant areas of potential investigation because we went back to a lot of the same old legacy researchers.

I know in the Combatting Autism Act it actually specifies some areas of investigation that were completely overlooked in those workgroups. I think we need to add on some additional steps to be able to gather more information and to look at some of the more out-of-the-box type novel ideas and then also special mechanisms for trying to fund those types of investigations.

DR. INSEL: Can we draw you out on that? That is really what this discussion is about. I think what I hear Steve asking is what would be the best way to do that going forward. Should we be thinking about additional workshops; should we be thinking about other ways of getting input. How do we make sure that we hear from people who people on the IACC feel that we haven't heard from enough. What would be the best way to do that?

MS. REDWOOD: I think you already answered that when you said webinars, town hall meetings, RFIs. Maybe vent the ones that we have right now and find out where the gaps are.

DR. FOOTE: Alison, did you have a comment?

MS. SINGER: Yes. I just wanted to point out that one of the other areas that I think was reversed in the order that we did them was when we originally looked at the process we expected to have the current inventory of funding prior to the meeting of the Strategic Planning

Workgroup. One of their charges was to help to set priorities to advise the IACC.

Since that hasn't happened yet, we might want to think about reconvening that group. I'm not sure why that group was disbanded, but reconvene that group to help us to evaluate the current level of funding, just to the point that you were raising earlier: what do we do when we have that data. Who is going to look at it. I think that may be the group that has the expertise to take a look at where we are and where we need to go.

DR. FOOTE: Good. This is the right kind of discussion to be having at this point. What are some of the general issues and what is the general sentiment of the Committee about things. So, other comments?

MS. REDWOOD: When we get the research inventory, will that include numbers, dollar figures for funding?

DR. FOOTE: Yes, yes.

MS. REDWOOD: Could we separate those out into the four areas of biology, treatment, risk factors?

DR. FOOTE: Yes.

MS. REDWOOD: I think that would help us to identify areas where there are gaps.

DR. McKEE: I know we thought that the RFI was widely disseminated, but just in the hallways at school I was asking parents, hey, did you see it, did you see it. Not a single person saw it. It might be that we are just dealing with parents who are in the trenches who aren't associated with the advocacy groups that posted it.

I don't know how you reach the people, but I like the idea of mixing it up a little bit with the town hall and the webinars so that more people can come forward.

DR. FOOTE: Yvette.

DR. JANVIER: Again, this is maybe a little too basic of a question, but in reading this law, the purpose of the strategic plan is to do what? Could you tell me?

DR. FOOTE: I think we might as well take this issue on because there are some misunderstandings about what is going on here and what the fundamentals of the exercise are. Your question is not too basic. Your question may well be the $64,000 question, for those of us who are old enough to remember when $64,000 actually was a significant sum of money.

[Laughter.]

DR. FOOTE: The strategic plan is to outline priorities for research dealing with autism spectrum disorders. There is a common misunderstanding that there is money associated with the Combatting Autism Act. There is no money associated with the Combatting Autism Act. There is no new federal funding created by the Combatting Autism Act. It is not like we have a pot of money where this strategic plan will determine how that money gets spent.

Obviously, the federal government supports a large amount of biomedical research, including autism research. Decisions are made about how to spend that money. Out of an NIH budget of $28- or $29 billion a year, somewhere between a fourth and a fifth of that money in any given year, there are new decisions made about how to spend it because the other four-fifths or so is already committed to multi-year funding.

There are a number of mechanisms through which those funding decisions are made. The way I look at the strategic plan is that it is a way for this Committee to develop and identify very high research priorities in the area of autism that all funders of autism research should be doing their very, very best to address in the near term, meaning in the next few years.

I'm just going to throw that out there because I know there are people who disagree with me and so on, but I think it wouldn't hurt to have some of those issues on the table. Of course, yes, what structure the plan takes hopefully will have some relationship to what its purpose is.

DR. JANVIER: I agree. I think it is a great purpose, and I think we have been operating under that assumption. But if you read this, it says the Committee is to coordinate all efforts within the Department of Health and Human Services concerning autism spectrum disorder, which means that the strategic plan should guide the dollars that are spent by the NIMH, or NIH or however you divvy it out, on autism spectrum research.

Again, that would make me question why is a group like the Simons Foundation, with lots of money in their coffers, sitting in our workgroup telling the NIMH how to spend the money? That really is the purpose of this group.

DR. FOOTE: Good question, good question.

DR. INSEL: Maybe I can clarify a couple of those things.

DR. FOOTE: Go ahead.

DR. INSEL: One of the things we will have to face is how to implement. One of the things that I think is great about the Combatting Autism Act, as I say, this isn't just for the government. This isn't just for NIH. This is to provide guidance for public-private partnerships and for cooperation across many sectors.

We are not interested in the Simons Foundation telling us how to spend NIH money, but we are very interested in knowing what the Simons Foundation is spending money on so that we don't spend the money on the same thing, or if we do, we do it in a way that is a partnership and we leverage whatever they have done.

I should just clarify that what Joyce presented was what we have done up until now. We have disbanded the workgroup. We have finished the workshops. All of that has been put aside. We now have a blank slate in front of us. We could do anything we want at this point.

If we want, we could bring the workgroup back. We could alter it in some way. As Alison suggests, we probably will need to have some group that is going to wrestle with this. It should be a group that has outstanding scientific expertise on it because, remember, scientific excellence was one of those guiding principles that we all bought into. You want to have people looking at this who are your very, very best scientists.

I would think that would be an important principle to follow. But how one would do that and what the group would look like and how much we would be involved are all the things that Steve is trying to get some guidance about.

MS. SINGER: I have to disagree with your comment that there is no new funding under the Combatting Autism Act. The Labor-HHS appropriations bill appropriated real dollars to fully fund the Combatting Autism Act less the across-the-board cut, which included real dollars for HRSA, real dollars for the CDC, and $108.5 million to the NIH.

The only way you can argue that there is no new funding is if you can say the NIH is already funding

$108.5 million, and we don't know that because we don't have the data and we don't have the inventory, which is why we have been asking for the data and the funding inventory from the time we first had this first IACC meeting.

Again, it is just imperative that we get that data because we can't proceed under the premise that there is no new money.

DR. INSEL: I think the group is, as they said earlier today, just about to deliver. They basically have the numbers. They are clarifying to make sure that everything really holds up. Even if they are off by 5 percent, I can tell you it is going to be over $108.5 million. In that sense, there is not money that will come in in the '08 budget that isn't already being spent.

The money that will be freed up will be dollars that are in that umbrella that are in four- and five-year grants that are completing. So there will be some churn. There will be money, usually no more than 20 percent of the overall expenditure, that would come free in any given year.

That gives you some idea of what kind of dollars would be on the table. Generally, some of that will be for projects that you will want to continue because they are very productive and they were already deemed to be really important to fund in 2004 and they may still be important to fund in 2008 and 2009.

So, even to assume that that 20 percent of the 108 or whatever the number will be is going to be completely free is probably misleading. It is going to be some fraction of that.

I think what would be important to realize for the Committee is there is really not going to be $108.5 million of unspent money sitting there waiting to be deployed through the strategic plan.

Having said all that, you could say, what are you doing the strategic plan for if there is no money. What is the point. I would argue that it is when you have so little to play with that you really need a strategic plan to tell you what not to do and to tell you where you want to put your next investments. Without this, you are just going to keep doing the same things you have always done.

It is in really sparse times that setting priorities becomes even more urgent than it would be when you have some money to play with and you can afford to make some bad investments.

DR. FOOTE: Yes, exactly right. On the other hand, it would be a mistake to assume that the strategic plan will not have an impact and will not have input. It will. These things do influence how funding decisions are made.

MS. BLACKWELL: Yvette was talking about the law itself a few minutes ago. It doesn't say a whole lot about the IACC, as we all know, but it does talk about the strategic plan and it certainly doesn't say what it is.

I got curious after our last meeting and, being a hopeless policy wonk, went and pulled the legislative history of the act and the committee report so I could see if there was anything there that would give me an idea of what we are supposed to be doing. I was just looking at it, and there is actually some language in both of these that might be instructive to us about what our further activities are.

It says in both the legislative report and the committee report the IACC will "serve as a forum to assist in increasing public understanding of the member agencies' activities, programs, policies, and research and in bringing important matters of interest forward for discussion." That goes a little bit further than the law does, but I think it is actually rather reflective of our previous activities.

DR. FOOTE: One more point of clarification about Yvette's comments. The issue of coordinating activities across HHS, my take on that is we have this research strategic plan which is focused solely on research activities, but then within HHS are all the activities like CMS and other agencies that are very large, very important, but aren't under the research umbrella.

The mandate of the IACC is to do the research strategic plan but then it is also a much broader spectrum of activities that include services activities. I think it is under that umbrella that the IACC has a mandate to undertake the kind of services activities that we were discussing this morning.

Any more comments about these strategic plan process issues before we proceed to talking about some alternatives about where to go from here? Other general issues that people have?

MS. BLACKWELL: Steve, under the FACA rules can we ever meet as a group without convening? Can we meet via Pictel or via phone conference to facilitate additional meetings, or do we always have to gather together like this?

DR. FOOTE: Physically.

MS. BLACKWELL: Yes.

DR. FOOTE: Well, the meetings have to announced and they have to be public. I actually don't know what the definition of "public" is when you are communicating electronically. I'm not going to guess. I'm not a lawyer.

DR. INSEL: Kate is here, but I think that a teleconference is not public. There has to be complete transparency for whatever the IACC does. Now, it is possible to have subcommittees or workgroups that would meet separately, but if it is an IACC meeting of the whole like this, it has to be in an open environment.

DR. FOOTE: That does leave open the question of whether we could have by some way, and I have no idea what the technology of this would be, a Web-based meeting somehow that anybody could view. I don't know if that meets the requirement to be public or not. We can look into that.

MS. BLACKWELL: We have meetings at CMS sometimes where certain people are coded to be able to speak and then other folks can just listen in. Kate, I don't know. Maybe that would meet the FACA rules. Maybe it is something you could look into.

DR. ALEXANDER: Yes, we have held meetings by telephone conference call on advisory committees that comply with all the requirements. The most recent one was a committee of genetic testing of newborns and infants. You have to advertise it in advance in the Federal Register. You have to make accommodations for public participation, and they get a call-in number so that they can participate fully, listening in and in a public participation time slot on the program they can make comments as well.

So it is possible to do that. It is a little bit complicated, but it is readily doable and works.

DR. FOOTE: Good. So that is an option on the table.

I think we need to now proceed to make some decisions about what we want to do from this point forward. I think I have heard over the total day from at least four or five people [the strong opinion] about the need to have at least a federal, and we hope a more comprehensive than that, inventory of research funding. People view that as being really important to how we proceed. That is something to keep in mind.

[Also], the need to get some public input. But as Joyce was pointing out, that needs to occur after the Committee reaches some preliminary decisions at least so we can post something [as] being from the Committee [that] we want the public to look at. That has to be sequenced in a way where the Committee has at least made some preliminary decisions about content before we have something to post.

We had divided this up into basically two scenarios: the current plan with some adjustments and another scenario, which is substantial additional input. I think the Committee has to decide do we need tweaking or do we really have a need for substantial new input. That is probably the first bifurcation of our choices. Then we can start talking about either the mechanisms for collecting substantial new input or the mechanisms for tweaking.

Does that make sense that that is the first big choice to make? Yvette.

DR. JANVIER: I just wanted to say that what you are describing is really one of the things that we are supposed to do. It seems to me that there are six things listed for what the Committee is supposed to do, but one of them is the strategic plan. Another is an update and summary of the advances in the research.

DR. FOOTE: Yes.

DR. JANVIER: I'm not as interested in the dollars. Of course I am as a taxpayer, but still, if 35 of our 41 initiatives have been addressed in the past year effectively with research, whether that was intramural, extramural, or private funding, that would be nice to know. I don't think the public or the Committee can make a decision objectively without having that summary.

The dollars are another side to it and it would be nice to see that, but I think there are resources in the program at the NIMH currently. People are sitting and reading the literature every day that is coming out. You funded some of that. I would love to see that information. I don't think we can make an objective decision without it.

DR. FOOTE: I understand the point you were making. I see it being also a broader question. We were actually going to take on this update issue after we finished this discussion, but you are raising a point. We have always viewed it as being an integral part of the strategic plan process.

This is another thing to keep in mind. The strategic plan has to be updated annually. The Committee is going to have to be making a number of decisions, both what is the process for getting Version 1 done and what is the, probably overlapping in time, process for launching whatever we are going to do to develop Strategic Plan No. 2.

At any rate, the update of scientific advances, which is an IACC responsibility to Congress, is certainly a step that we would want to undertake prior to at least the next version of the strategic plan. We could undertake that for this version of the strategic plan as well if that is the Committee's wish.

We did do a data call and collect advances from ourselves and a number of organizations. We do have that information, and that can be shared.

DR. INSEL: I think what Steve has up here is the question about how we do that. Does this group want to operate as a workgroup to get this done? Do you want to delegate someone else to do the work and advise us? I think we are really stuck on this issue.

There is a lot to get done here. There is a huge amount of data to go through. There is a huge amount of information to try to synthesize, organize, and prioritize. Who do we want to do this?

DR. FOOTE: Lyn.

MS. REDWOOD: I guess I'm thinking that the Combatting Autism Act passed in what, 2006?

DR. FOOTE: Yes.

MS. REDWOOD: We knew this was something that we had to do. I would think that NIH would already know this, like what they are funding and what they have been funding for autism research, and the budget, and it wouldn't be that hard to get this information together. I really wish we had it before now. I'm just scratching my head as to why we don't already have this.

DR. INSEL: We do. Every year we report a number for research that is coded for autism across all the 27 institutes and centers both as dollars and number of projects and information that goes with that. What we didn't have was taking those 380, or something like that, grants and separating them into these four bins to see how do they match up with what is coming up in the strategic plan. That is what has taken six weeks or five weeks, whatever.

It is essentially done, but we didn't bring it today because we want to make sure it is truly accurate. There is still some tweaking to do.

DR. FOOTE: The 2007 numbers weren't available until February. Am I accurate in that statement, that it was February that they were available.

DR. INSEL: To give you 2005 and 2006 numbers I didn't think would be that helpful. This will be available. It is something we can work on going forward. I'm trying to figure out who is going to do the work and whether you want to separate out.

MS. SINGER: I think a lot of the expertise we need to evaluate that data, when it becomes available, is housed in the Strategic Planning Workgroup. I think if we look to maybe add a few more people to build out that workgroup, I think that is the group to do it.

Back to the question, though, about the data, it is not just a question of getting the 2007 data because we have seen data in 2006 and we have seen data in 2005. The problem with the data is that when you add up the spending by diseases it adds up to about three times as much as the overall NIH budget. What we have been asking for is the specific spend with regard to autism because the Combatting Autism Act specifically directs spending for scientific research in autism spectrum disorder.

My hope is that when we see this data it is going to be the studies that are specific to autism spectrum disorder and not including the studies that are for schizophrenia and depression and a wide range of very important, important diseases. We certainly don't have a monopoly on suffering in autism spectrum disorder. That is not what I'm saying.

The Combatting Autism Act specifically speaks to autism spectrum disorder. My hope is that when that data comes it will look only at ASD.

DR. INSEL: I do need some clarification on this because where you will run into trouble, or where we run into trouble with this is if there is a project that studies autism in children with Fragile X. We tend to count that both for autism and for Fragile X because it seems to us that it is relevant to both.

But you are right. Then we end up double counting, and when you put it all together, you end up with a number that is bigger than 100 percent.

It seems to me that if the question is what are you spending on autism, to not count a grant that is looking at autism and Fragile X kids wouldn't be accurate, either. It would be better to count it. I'm not sure what the right answer is for that.

MS. BLACKWELL: I'm not even sure that this law restricts us to research within NIMH, does it?

DR. FOOTE: No.

MS. BLACKWELL: It says "research."

I have another question. We talked about --

DR. FOOTE: It is not going to be just NIMH numbers. It is going to be much broader. It is going to be all of NIH.

DR. INSEL: CDC.

MS. BLACKWELL: You might want to check with CMS.

DR. INSEL: Is there research through CMS that is going to connect with these? If there is, we would love to see it.

MS. BLACKWELL: I think it is possible that some of our research on home and community-based services for people with disabilities could be. You could draw an analogy. I don't know if we can pick out the numbers of people with autism, but you might want to look at it.

DR. INSEL: This would be really helpful. [Do you know] if CMS codes for autism?

MS. BLACKWELL: We are working on it really hard.

DR. INSEL: This is the problem.

MS. BLACKWELL: Really hard. In fact, I talked to Ed Trevathan last week, and we would like to get together a separate group of folks that are interested in looking at the numbers to further delve into could we work with each other.

DR. INSEL: I think it is a great idea, but this really starts to get into Alison's question about trying to identify research that truly is focused on autism and not on a range of other problems. I'm not saying we shouldn't do it and we certainly don't want to leave it out if it is there, but we would need to make sure that we can defend it and that it really is in the spirit of the act. I think that will be important to look at.

MS. SINGER: Again, I think the way to involve stakeholders in that process is maybe to reconvene the Strategic Planning Workgroup.

DR. INSEL: Can we get some feedback from others about that? That is the first question mark under "Decisions." We need to get to some decisions here.

MS. REDWOOD: Personally, I would rather see a workgroup that was a little bit more diverse than what was in the first workgroup that we had. I think we need a combination of researchers, clinicians, stakeholders, and people with autism. It needs to be much broader.

There is also language that was attached to the Combatting Autism Act that allowed for the development of an Autism Advisory Board. I would like to suggest that that be considered as another way to vent these types of issues, to get some ideas with regard to how we categorize these areas of research, and to review over our strategic plan every year. I would like to throw that out as an alternative to reconvening the workgroup.

DR. INSEL: Other thoughts or other responses?

MS. BLACKWELL: I'm wondering if when we reconvene the workgroup, if the workgroup has to be limited to those folks or if there are IACC members that want to be informally part of that workgroup or formally part of the workgroup and who are available. Shouldn't they be permitted to be a full part of the workgroup?

MS. REDWOOD: And for the meetings to be open to the public. I think that is crucial.

DR. INSEL: Other recommendations?

[No response.]

DR. INSEL: What I'm hearing, just to make sure I'm getting this right. Steve, in terms of your first question, it sounds like people would like to see a workgroup convened that might include some of who was on the workgroup before, adding in additional members, including the IACC, having it an open process, and making sure that the group begins with a portfolio.

DR. FOOTE: Right. An inventory.

DR. INSEL: Have we captured the spirit of the group? Having said that, are there people around the table who would like to serve on such a workgroup?

[Show of hands.]

DR. INSEL: We have a couple of hands. Three, four, five, six. Now, I want to remind you that the point of having a workgroup is to have a group that can advise us. The reason why we didn't include the IACC on the first workgroup is it didn't make sense to have us advising ourselves. But if everybody wants to be on this group, we can certainly do that. It just doesn't sound, I think the word "efficient" was the one that Cathy used before. I'm not sure it is the most efficient use of our time.

They are going to bring ideas back to us that we can then accept, reject, or modify. But if people feel that it would be worth being there for the original discussion and being part of it, we can do that. It is your workgroup. This is your process. You decide how you want to use it. Cathy.

DR. RICE: [Would an option be] instead of being the IACC members themselves, each member can appoint someone to be on the workgroup? So, a scientific advisor potentially but not the actual IACC member. It might just be one step removed, but at least we are not just advising ourselves then.

DR. INSEL: If I could reflect on that, again just a personal response. That does seem to me to get us more. There is value added in bringing a new person into this process rather than us advising ourselves. Then you hopefully will have someone whom you feel has the same diversity. At least we should have as much diversity on this group as we have here at the IACC.

How do other people feel about that?

DR. JANVIER: I was calling it the executive committee. If you are looking for a group to advise the small number of employees that are working full-time on the project to drive things forward with the sense of urgency that we have, I don't see any problem with some of the members of this Committee being on it. I myself don't have the time to be running down here every few weeks, but I think that is a positive, having some of our members from the larger Committee.

We can't get everything done here. We don't have the time, we don't have the skills. But to support the full-time employees to drive the process forward I think would be positive. Again, I don't know the government terminology. But, something like an executive committee, a smaller group that is supporting the full-time employees to drive things forward in between our meetings.

I do think the meetings need to be more often. At least quarterly, maybe every two months.

DR. INSEL: Other responses?

MS. REDWOOD: I just have a question. I heard two things. I heard that the workgroup, if we reconvened a workgroup, would look at the research inventory but then also advise us. I guess I would like to have the research inventory before our next meeting. So, if we need a workgroup to be able to categorize that information and get it to us, but then let us make the decisions as well with regard to what the next steps are, if that makes sense.

DR. INSEL: The research inventory, at least for NIH, will be done before the end of the month. That is the easy part. What I'm still trying to understand from you is who will use that to take where we are and move the strategic planning process forward. Are you okay with the workgroup doing that as well? Does the IACC just want to do this and bring in the scientific expertise? I guess I'm getting confused about what you want.

MS. SINGER: I think that is how we bring in the scientific expertise. I think there are a lot of us around this table that want to be involved, but also looking around this table, there are no scientists seated here. I think they may be in the best position to make -- I'm sorry. Well, no NIH-funded researchers.

[Laughter.]

MS. SINGER: I apologize, I apologize. I

apologize.

There were a lot of great ideas that came out, and I think we captured that in the workshops and the workgroups. They can really provide important information to this group. I think we saw a lot of that come out of the meetings.

I would say that is a great place to start. Have more scientists who are in the field doing the research who are getting the NIH funding now, to understand what they are doing and where the holes are.

DR. INSEL: I'm getting two messages. This sounds like convening a workgroup that looks a little bit like the old workgroup but adding people in. But then I'm also hearing that the whole IACC wants to do this itself, either without a workgroup or in parallel to a workgroup. What is the sense of the group here? Peter.

DR. van DYCK: You have professional staff. It seems to me the professional staff have to do the writing and the pulling things together. The way I would sense it is this workgroup, however it is constituted, provides input, but then the professional staff, it seems to me, has to actually do the writing.

At that point, it can come out to us without meeting. It can be Emailed to us. We can correct it. We can offer suggestions. There has to be an iterative process with periodic bringing to the whole Committee on a face-to-face meeting.

If we are talking about process, I certainly, as a member of the IACC, don't want to write a strategic plan. I want to be able to have input and to review and to provide guidance. I don't want to be the person or part of the group that writes it.

DR. FOOTE: Darn.

[Laughter.]

DR. INSEL: You disappointed a lot of people with that statement. Well, that is one person we can't stick it to.

DR. FOOTE: We have many steps to go until we are at the stage of even having a draft. Yes, it has been our assumption that the staff will have primary responsibility for generating a draft. But we are still a long ways away from the draft. The question is how do we get from here to a draft strategic plan.

DR. INSEL: One of the things that I think we may be missing here is that what is going to be most useful, I think, in the plan will be setting priorities. The priorities ought to be generated by just the kinds of questions that Joyce was showing us before. What is the greatest public need.

But it can't be only that because you also have to have that intersect with what is scientifically feasible. Where is the scientific opportunity. I'm not sure that we as a group know that. That is where you want to bring in people who are on the cutting edge of science, who know what is the most important discovery in the last week and what is going to be the most important discovery in the next two months, and how it can be related to autism and really move things forward.

I want to make sure we are getting that kind of input. Maybe we have gotten enough of that already?

DR. FOOTE: Let me try to make a suggestion here. Actually, this conversation is going on for quite a while and we haven't made any decisions yet. I think we have had some useful discussion, but we haven't made any decisions yet.

It sounds like the inventory is a crucial element. It sounds like the Committee needs possibly to have some more structured alternatives from us to discuss and make decisions about, and that we now have some additional input about what your general thinking is so that we could possibly do that. For example, propose three alternatives about what the structure of a reconstituted workgroup could be and how to proceed with that.

Now, there are two options about that. Either we can try to resolve that right now and take a vote right now, or the team could come back to you before our next meeting, which is two months from today, with the inventory, which probably we can have in three weeks, with some of these structured alternatives about how to proceed. Then, at our May meeting, we can take some votes and decide with some specificity how we are going to proceed from that point forward.

Alison.

MS. SINGER: I would hope that we could make some decisions today because the appropriations bill under which we are funded is for 2008. We are in 2008 now. We are now missing our opportunity to provide our input.

Similarly, the committee language accompanying the appropriations bill directs the director of NIH to report back to Congress on the progress of the strategic plan, including the funding levels for the components of the IACC strategic research plan, on July 1st of this year.

I think we need to try to move the process along in keeping with our number one value, which was our sense of urgency.

MS. BLACKWELL: Steve, I have a question. We have done a lot of talking about the strategic plan, but it also appears that the law requires that we develop and annually update a summary of advances in autism research.

DR. FOOTE: Right. Correct.

MS. BLACKWELL: What are we doing to effectuate that process?

DR. INSEL: We will come back to that at the end. We have an agenda item for that.

Alison, do you want to make a recommendation?

DR. FOOTE: Do you want to make a motion?

MS. SINGER: I would make a motion that when we receive the inventory at the end of March, or that we schedule now and plan now for a meeting of the Strategic Planning Workgroup to take place in April so that we can start to review the inventory and have the workgroup start to make some recommendations on priorities to this larger group, and that that happen at the May meeting, not that we wait for the May meeting to first empower the workgroup.

MR. GROSSMAN: I will second that.

DR. FOOTE: I think there is enough specificity in that motion. I'm sorry. Lee, you were saying you second? I'm sorry.

Tom, you are the chair of the Committee. I guess you ought to conduct this discussion and vote.

DR. INSEL: I have a motion, then, to convene a workgroup. If I can add, just to make sure I know what you are saying, this would be the workgroup that we had before with additional people to be recommended by people around the table. The meetings would be open to the public.

I also hear that many members of the IACC would like to be on the workgroup. Is that still in the hopper? So this is going to be a very big workgroup. It will be twice the size of this group. Is that the motion?

MS. BLACKWELL: I'm not sure if the composition of that workgroup has to be what was convened initially and then expansion or additional. What about the possibility of just taking a subset of individuals to represent the initial workgroup and then building around that nucleus?

DR. INSEL: So, how are we going to decide who is on the workgroup? We could be here all day figuring these things out. We did it before by my just taking the prerogative of the chair. I got a lot of heat for that later, so I'm not sure I want to do that again. But it was efficient.

[Laughter.]

DR. INSEL: We have three or four different notions of what this workgroup would look like. I really do want to suggest to you that once it gets beyond 15 people it is a convention, it is not a workgroup, and it is not going to be effective. I think you want it to be inclusive but you don't want it to be expansive.

We need some guidance about who you want to have in this group and how to do this.

MS. REDWOOD: I think Cathy had a suggestion that each member pick someone that would represent them that would be on the workgroup. Would that be fair?

DR. FOOTE: Is that to establish a slate of nominees for possible participation in the workgroup or membership in the workgroup or is that to be the group?

MS. REDWOOD: To be the group. Does that sound fair?

MS. SINGER: Although maybe we wouldn't require that everyone do it. I don't want to put the onus on everyone to have to come up with someone if they don't have someone. Maybe if we want to we can suggest someone but not require it of every member of the IACC to put a name forward. Those names that did come forward would be included.

MS. BLACKWELL: Just to add to that, everyone could do a maximum of one, but some people could pass.

I would also say the caveat that hopefully the guidelines of who should be nominated would be somebody with scientific expertise to some degree, however that is or is not defined. But that we are not talking advocacy in general, we are talking about scientific expertise.

MS. REDWOOD: I disagree with that because I think you need both. I think you do need the advocacy voice in there. You need the stakeholders in there, especially if we are going to be making decisions or if we are asking this group to make decisions about what needs to move forward with a sense of urgency.

I think a balance of both would be ideal. If we could somehow get together and say there are this many people. Are you recommending a scientist or a consumer advocate.

Also, just a point. When we get the research inventory, will it include findings? I think it would be real important to have a dollar amount and then what came out of it.

DR. INSEL: The inventory will be 2007 funding. It will be dollars, percent of the portfolio, and areas. There is a document that we are required to send to Congress every year, and that is a separate document that will cover findings from 2007.

MS. REDWOOD: Will we capture findings from

2005 and '06 as well or no?

DR. INSEL: We have documents that we send in every year that summarize what has come out of the autism effort. We can share those with you.

I'm sorry to obsess, but I'm trying to understand what we are about to vote on for the workgroup. You are talking about each person being allowed to nominate one member. Do the members of the IACC also want to sit on that workgroup? Or is this an either/or, either one would sit on the workgroup or would nominate somebody? Chris.

DR. McKEE: I would like to be able to watch. I watched the workgroup last time. Even if we are not active participants, I gained about a $5,000 education in that few hours just because the medical terminology doesn't spin off of my tongue. I think that having us there, we educate each other from our different perspectives.

If the workgroup is actually going to take the scientific research inventory and compare it with our 41 initiatives, I think that is mostly a scientific endeavor. There are services listed on there as well, services and treatments that we can talk about.

But, even if we are not formally on it because then it makes the group 24 or 25 people, I would certainly like the opportunity to sit in and watch the deliberations.

DR. INSEL: What is the sense of the group? Now we are talking about having IACC members as observers, having appointees from the IACC as members, and also including, if I understand right, some of those, perhaps all of those, who were on the previous workgroup. We would have the scientific expertise based on the workshops and we would have additional members coming from this group by nomination.

DR. LANDIS: Isn't that going to end up 30 people? Instead of having all of the members from the previous workgroups, could you ask the chairs to represent them to keep the numbers down? That would be four people.

DR. INSEL: That is the motion and we have a second. All in favor?

[Show of hands.]

DR. INSEL: Anyone opposed?

[No response.]

DR. INSEL: Steve, I think you have done it.

[Motion carried.]

DR. INSEL: So there will be a workgroup meeting in April. We will get the inventory out well before that. The workgroup will be made up of the chairs of the workshops, if they are still willing, as well as nominees from this Committee. The meetings will be open, and the members of the IACC will be specifically invited to attend.

AUDIENCE MEMBER: [Off mic.]

MS. BLACKWELL: I would highly encourage that. I think it would be great. As I said, we do this all the time at CMS, and it works almost seamlessly.

DR. FOOTE: Joyce, come to a microphone, please.

DR. CHUNG: I just simply said that since we have to actually make it happen that we would like to try to do this virtually. So it could be on the Web. People can listen from the public. That is how it could be open. We have to look into the logistics and the rules, but I imagine it is probably possible. That way even

IACC can come virtually, participate, and observe. We could really open it up.

The workgroup members might not be able to come, let's say. Maybe they can't come, but they could speak. They would have a speaking privilege so they don't just listen. But we can do, I think, things like that, which could make it happen. Just think of the logistics of trying to get something done in the next month. It is just impossible. So we would like to try to do it that way, if it is your pleasure. We will try to do it that way.

DR. INSEL: I see heads nodding.

PARTICIPANT: It really does work. In our meeting, we had more people sign in from the public and participate than we did members. It works.

DR. INSEL: Great. It is even less expensive, so we will have money to spend for research instead of for meetings.

DR. FOOTE: Let me address one more issue. The charge to the workgroup at this April meeting of theirs is to review the inventory and to develop a proposal to the Committee as a whole about how to go forward. That would be for your review at your May meeting so at the May meeting we can decide how to proceed. Is that the idea? Alison.

MS. SINGER: I think we want them to look at the inventory and also look at the 41 ideas that came forward, knowing that at least four of the member will have been involved in the production of those ideas, and then make prioritization proposals to the larger IACC for us to consider in May.

DR. FOOTE: Good.

MS. BLACKWELL: I'm a little bit concerned with the guidance to give this new workgroup once we get the inventory. I think we are all assuming that it will be very obvious. You are going to match it up with the initiatives and maybe it will be clear. If there is no money being spent on Topic X, that will be obvious. But, how are we going to guide them?

In some cases there might be a lot of money being spent because that is an area that has a lot of traction. I don't think we want to give them the suggestion that areas where there is now a lot of funding are necessarily ones that should be taken off of the table.

I just think maybe we are thinking this inventory is going to be matched up with these initiatives and it is going to be very simple to know how to proceed. I don't think it is going to be simple at all.

DR. FOOTE: Anything that the Strategic Plan Workgroup proposes is subject to the review of the Committee as a whole. I don't know if that addresses your concern, but that is certainly true. This is the issue of delegation. Are you going to delegate.

MS. BLACKWELL: Ideally, I would like to see the chairs of each of the workshops be here at the May meeting so that we can ask them. Catherine Lord, you have this great tool. You chaired the committee. These are the priorities. In the old matrix you had the high risk/low risk type of concept. This is doable, it is not doable. With $5,000 we could push this through and it is going to have a great impact.

I think having the scientists or the leaders who ran these workshops would be very, very helpful so that we can ask these questions.

DR. INSEL: We can make sure that they are here for the next meeting. Getting on their schedules has never been easy, but we can figure out a way to work around that.

DR. FOOTE: It is two days before the MFAR meeting in London, and probably a lot of them will have ancillary meetings in London a day or even two days prior to the start of the MFAR meeting. So we will do our best.

DR. INSEL: I'm mindful of the time. We have other things to get done here. Let me just clarify one more thing. One other thing you told us earlier was that you want to make sure that we are getting more ideas in at the same time that we are narrowing this down and bringing this to some priority decisions.

I would like to make sure that you are comfortable with the Autism Team getting out and doing that, whether it is through town hall meetings, webinars, or whatever we do. We would like to move very quickly over the next month or two months to make sure that we are getting more information that might not have already come in through these 41 initiatives.

Having these gives us an opportunity to put something out there as a straw man that people can respond to. We already heard this today, that there were pieces that people around this table felt might be developed better. I think that would be really useful, so I want to make sure that is okay. Duane.

DR. ALEXANDER: With regard to that, one possibility for doing that, and it could be done separately from the inventory review, is to publish for public comment the suggestions that we got from the workshops, the 41 ideas of research topical areas, either grouped by the four workshops or grouped by the five or six items in the matrix, for comments. Comments on these as well as suggestions for other areas that fit into the matrix and other suggestions for research.

If we do that, we can do it through the Federal Register and get public comments back and perhaps even have it in time for the May meeting so it could be considered alongside the recommendations with regard to the inventory that are coming from the workgroup.

DR. CHUNG: You act like people can respond to a title of an initiative in a substantive way. These initiatives have a lot of details behind them. They are 41 with a lot of details. It is not something a public member -- I can't respond to it and I'm a psychiatrist.

The thing is, is that it is easy to say we can get some feedback, but how meaningful is it and how substantive is it? How can they come up with something with that level of detail?

I just wanted to say, when you organize them in those bins with the questions there are these initiatives but they are just the titles. There is so much underneath. That is the detail, the sand. I know what you want us to do, but I don't know what we will do with the responses, is what I'm saying to you.

DR. INSEL: I'm already hearing from parts of the community that say we haven't had a voice, we have been left out here. It seems to me that the next step might be, even before we put this out again, to get their voice into this process to make sure that the points they think are really important somehow get included and get mapped onto this framework.

Maybe at that point, when we have a document that we feel is ready for a re-read or an editing process, might be the time to take this back out for another RFI.

We have learned over and over again that you can't do enough in the way of public input. There is always a good reason to do that late in the process as well as early in the process. It is just a question of how late. I would think that we might want to do this after we have a little more information into this matrix. Ellen.

MS. BLACKWELL: When the workgroup meets you were talking about having them rank the 41 proposals. Could they also look at them for us to see places, because they are the experts, where some of these initiatives could be consolidated? It seemed to me in reading them that there is overlap. Although we have some scientists with us today, they have the expertise, perhaps more than we do as the IACC, to see areas of overlap and where a lot of these could be consolidated.

We started with zero. Now we have 41. Maybe they could boil them down to 20 for us. That would be very helpful to us as a group. I think we might be able to understand them better.

MS. REDWOOD: Tom, I know that in the 500 requests that we got in from the RFI there were some wonderful things in there. I don't see them captured in the 41 that we have. Maybe even to go back through those. I know that even one of the workshop chairs acknowledged that they hadn't even looked at those. We gathered all that information but I just don't know that we have really utilized it the best way we could have.

DR. INSEL: We still have that. It is still available. We can share it with the Committee. That was done in a very formal process. We had a writer who came in and actually took all the RFIs and put them into some more readable form so the workshops could use them, but it didn't happen in some cases. These are really busy people who might not have opened anything up until they got on the airplane. That is the way it happens.

It is always the struggle you have. You want to get the very best scientists in to help on something like this, but they are the people who have a hundred things going on at once and the amount of time they can give is often very limited.

I have the sense that people are exhausted. I think this was an important discussion to have. I know it wasn't by any means inspiring, but there is no other way to get at this. We really want to make this a process that the IACC wants and not something that we have just cooked up. So I appreciate everybody's input. I think we do have now a better sense of how we should go forward. Certainly I'm happy that we haven't lost that sense of urgency.

A couple of people have brought up other issues about the IACC's functions in terms of the reports on advances and how we handle that, and this very important issue about public participation. I think we do need to get back to those issues. I don't know that we want to do it right now.

I was going to recommend that we take a five-minute stretch break and then reconvene for the next part of the meeting.

[Break.]

DR. INSEL: We are going to reconvene for the final session. The very important part of this meeting is the section at the end of the meeting for public comment. For this particular meeting we had a huge number of people who have written in who wanted to make public comments. On the website what it says is that in order to do that we need to have your written comments 10 days before the meeting and that they should be restricted to five minutes, but if we gave five minutes to everybody who has written in to read their comments, we would be here until well past dinnertime.

We have been trying to figure out how best to deal with this, and I think in the spirit of fairness what I would like to do is to invite the people who have written to us to make comments but to ask them to keep it to one minute, or maybe a little more than that. Otherwise there will be no way that we will get this whole group of people through, and it didn't seem fair to us to allow only some people to speak. I understand that is a hardship for some, but I hope you can bear with us.

We will need an extra chair for the extra microphone.

The first name on the list is Paula Durbin-Westby.

I should clarify that everyone's written comments will be entered into the record and will be available on the Web. So whether you read them here or not, they will be available to the IACC and anyone who wants to access the IACC website. The problem for me is when I looked at this long list, which I just received, I don't know how we would be able to get everybody in here with these very long comments between now and 6 p.m. It is just not feasible.

PARTICIPANT: [Off mic.]

DR. INSEL: Sure, absolutely. Paula, right here. You get the throne up here.

The way we do this generally is just introduce yourself and then we will give you some idea of when the time is running out. The chair will shake or something like that.

[Laughter.]

DR. INSEL: Thank you very much, though. Welcome.

MS. DURBIN-WESTBY: I'm Paula Durbin-Westby. I'm an autistic self-advocate. As an autistic citizen and taxpayer, I have an interest in how the funds from the Combatting Autism Act are allocated. I thank you for the opportunity to speak to you today.

My concern is that research priorities should not be driven primarily by emotionally charged language used by fundraising organizations or having a disproportionate allocation of funding to research that may have limited application for autistic people and their families and care givers now.

We need accurate and well informed research into the real lives of people on the autism spectrum. A large part of the focus needs to be on treatments and interventions that will be beneficial. Especially, studies are needed into effective service delivery across the life span, as we have talked about here today.

Community-based participatory research is a promising avenue for exploration because with community-based research persons affected by the condition are full participants in every stage of the research process outlined in a recent funding opportunity announcement for community-based participatory research to medically underserved communities, which can often include autistic people as homeless or people who don't have health insurance or are falling through the cracks in other ways.

In that document, "community" refers to populations that may be defined by a number of parameters, including disability or health condition, or to groups that have a common interest or cause. The autistic community, while not a monolithic voice, fits that description in the federal funding announcement.

Treatment research also must include people on the autism spectrum. I noticed that there were no individuals on the spectrum on the Treatment Working Group that was convened recently.

Treatment studies that focus only on trying to make us seem or to be neurologically typical can have really detrimental effects. There are many anecdotal stories of people becoming really stressed out in their 20s, 30s, and 40s after a lifetime or many years of pressure brought on by trying to adopt behaviors that are not really natural for us.

In this area it is crucial to consult with people on the autism spectrum to determine the best methods for interventions and treatment. Adults who can communicate or have had experience with autism are one of the best resources for determining which treatments and interventions will help without causing unintended damage.

Any studies taken without the participation of people on the autism spectrum can be marred by incomplete knowledge of the population being researched. Members of the autistic community should be collaborators in the research above and beyond merely being research subjects.

A team science approach can be incorporated into all areas of inquiry, including the four areas of diagnosis, treatment, intervention, biological factors, and risk factors.

I'm glad to see Stephen Shore is a member of the IACC. I didn't notice anybody else on the autism spectrum except for there was one person on the Biological Working Group, I think. I think especially treatment research but I think in all of the areas some kind of protocol could be developed to include people on the autism spectrum at at least the front and back end of the research process.

DR. INSEL: Thank you very much.

MS. DURBIN-WESTBY: Thank you very much.

DR. INSEL: Thank you. Michael Frandsen.

MR. FRANDSEN: Thanks. I'm trying to edit a lot of this out. I will try to make it as quick as I can. My name is Mike Frandsen from CoachMike.net. I tutor kids with autism.

I believe the NIH is doing good work in autism research, but there has been some discussion that NIH should do some more research on services and coordination with services for people with autism. One example of how this disconnect between research and real-world services can be partly bridged is greater federal employment for people with disabilities.

I believe one area that is deeply ingrained in the NIH culture that needs to be changed is the insistence that NIH is solely a research organization whose responsibilities completely end at conducting research. This shows a reckless disregard for coordinating with the services that are desperately needed today to improve the lives of people with autism and other disabilities.

This attitude is at best short-sighted and at worst a mind-set perpetuated by academics who sit in ivory towers rather than work in the trenches and help with people with autism and other disabilities.

During each of the past five years I advocated on behalf of a person with impeccable credentials and great experience who has a psychiatric disability to get a job interview at NIH through the Schedule A hiring authority. Schedule A is a federal program used to appoint persons who are certified that they are at a severe disadvantage in obtaining employment.

While the person who I advocated for does not have autism, FOIA requests I sent to NIH have shown that as of a year ago not one of NIH's employees hired in the previous five years was hired using the Schedule A authority for people with disabilities. There is no evidence that during this time frame the program was ever used at NIH to hire someone with autism or on the spectrum.

Information received each of the past five years, multiple times per year to the NIH director, HR contacts, EEO representatives, selective placement coordinator, communications directors, and the ombudsman.

Even years after NIH was notified of the problem of the lack of Schedule A hires, they refused to do anything. NIH's response has been insensitive, ignorant, and dismissive, and I left my job at NIH in protest a year ago.

It is ironic and disappointing that an organization whose mission is to work to improve mental health through biomedical research on mind, brain, and behavior, the NIMH, does not have an equivalent program to ensure that people with disabilities can fairly contribute to advancing that mission.

I believe that NIH and other agencies should not only develop policy on making the hiring process as inclusive as possible but should also be accountable to these claims by ensuring that the policies are effectively implemented in a way that will mutually benefit the agencies, the public who they represent, and the employees who conduct work for these agencies.

NIH and other agencies need to do more than just say there must be many people who happen to have disabilities among our 17,000 employees. NIH needs to be proactive in hiring people, and other operating divisions of the Department of Health and Human Services need to take a role in outreach and awareness.

In conclusion, given its position as the steward of medical and behavioral research for the nation, NIH should be particularly sensitive to attracting and retaining people who are traditionally underrepresented, including those with disabilities, whether they be physical, psychiatric, cognitive, or developmental disabilities.

Incidentally, there is no category for developmental disabilities in the Schedule A program. A failure to proactively include employees from all segments of society in the hiring process threatens to leave these people languishing with difficulties and frustrations. This is based partly on what I have written on my website, CoachMike.net. Thank you.

DR. INSEL: Thank you. Dena Gassner.

MS. GASSNER: I brought my own timer.

[Laughter.]

MS. GASSNER: Thank you, Dr. Insel and

Committee Members, for your time, commitment, and passion. With all due respect to differing opinions, pain and suffering should not be subjectively measured by persons who rely on simple observation and emotionally charged reactive empathy. We look at a small child or a child we would perceive as profoundly disabled and we have great empathy, but when we see that level of impairment in an adult we no longer have that empathy.

Most individuals regularly experiencing the most consistent discrimination do not draw to them the empathy, patience, understanding, and most importantly, support. Nearly all of these persons are costing each day.

Through the medical school and now NCLB models, we are placing on children with ASD a higher goal than we do on typical children. We do not want them to be whole, complete, and healthy individuals living successfully with a difference. We want them to be normal. That for us is an unachievable goal. Becoming whole and complete and successful defined by our own individual personalities is very achievable. We need a paradigm shift toward that direction.

I have come here today to tell you that having an ASD did not disable me. I received my master's degree with honors prior to my diagnosis. However, living in a culture of intolerance without adequate supports failed my mother before me, myself, and my son, who is sitting downstairs watching movies today.

Today these people who stand before you who have autism differences, please stand if you would like to be recognized. We represent pharmaceutically an illegally altered drug and cost to people who are just desperate to quiet a noisy brain. Fear of transition combines with an insatiable desperation to be accepted and unconditionally loved, something, by the way, the medical model does not encourage us to accept and have. It results in domestic abuse, workplace harassment, and fiscal manipulation in our society.

Topic X came up earlier today, and that would be that hallway conversations with leaders in Asperger syndrome around the world will tell you that the ratio of men to women is not four to one in their practice but closer to two to one. We have not a single initiative in this nation to help women with autism differences. They are our mothers, they are our sisters and our partners. They represent a huge part of the homeless population. We are incapacitated by red tape and inaccessible loopholes and a lack of access to mentoring and surrogate representation for our children at IEP meetings.

I will close my statement from my own personal perspective at this point. My son's name will come up for a public statement a little later, and I would like to speak on his behalf. We drug him all through the capital yesterday seeing his representatives and he has nothing left to give, but he does have a written statement in the record and I will be sharing his point of view about where life with autism is for him at that point. Thank you very much.

DR. INSEL: Do you want to do that now just to save you time?

MS. GASSNER: Absolutely, sir. I can be very expeditious.

DR. INSEL: So this is for Patrick Kelty.

MS. GASSNER: Yes, sir.

MS. GASSNER: Patrick's statement basically expressed that he has had two positive experiences with public education. One is at the fourth grade level, and just last year. He wants you to know that we have relocated out of the State of Kentucky, through the State of North Carolina. We went from neglect and ignorance in Kentucky to intentional and malicious abuse in the State of North Carolina.

We left North Carolina, where they unilaterally took him out of the diploma track to even have access to the academic curriculum and moved to another place, which I won't mention because I don't want to suck up all our resources, where he is having a wonderful experience. He got his letter for hockey last week, for managing the hockey team.

As all the other players got their awards, polite applause went through the room. But as my son got his, it was a standing ovation, because not only did Patrick achieve but every child in there and every parent associated with that child understood what an achievement it was for Patrick.

He represents the bottomless pit in terms of service delivery in our nation, because through the grace of God and the tremendous amount of effort, and $100 a week in tutoring we may actually help him to get a high school diploma, despite years of neglect.

However, I sit on a post-secondary task force in my state whose one goal and objective is to provide programming for children who don't graduate from high school. He will be left with no services, even though he clearly needs those services. The ADA for university placements is not broad enough to encompass the kinds of life-skill support Patrick will require, and many, many other students, many who take AP classes, many who are academically brilliant kids, who crash and burn after two weeks.

I heard a story from one of my sisters today, that she was in a mental health breakdown shortly after going to university because the services aren't there.

Then we are discriminated against because voc rehab is, without a doubt, one of the most dysfunctional systems we are working with.

This summer, for $1,000 a week, I will be sending my son to Denver to try to learn what everybody denied him for these years. The only other program that will be available to him at that point will range between $16- and $32,000 a year for him to become a functional adult.

I was at the Holocaust Museum yesterday, and I saw this on their wall. It really moves me, so be patient with me if I don't make it through. The poem says, "Wild grasses rustle over Babi Yar. The trees look ominous, like judges. Here all things scream silently. Baring my head slowly, I feel myself turning gray, and I myself am one massive soundless scream above the thousand buried here."

We need to be screaming. These people who were in the Holocaust started out by just being ignored and by people being silent. I went to my legislators and said, "You see two constituents but our elbow-to-elbow contact with people who love this child represent 200." We have to start screaming with those kinds of numbers if we are going to make change. Thank you.

DR. INSEL: Thank you. Sharrill Hemry.

MS. HEMRY: That is a hard act to follow. Good afternoon. I urge the IACC to place a high priority on interventional trials of immunomodulatory and anti-inflammatory drugs to safely target neuroimmune and neuroinflammatory issues as they relate to autism spectrum disorder in support of U.S. Code 42 Section 284G of the Combatting Autism Act.

There is increasing awareness that the neuroimmune system and neuroinflammation may prove to be the key components in the etiology and treatment of ASD. The best highlight of this came in 2005 when the Johns Hopkins University School of Medicine published in the Annals of Neurology and the International Review of Psychiatry the first proof of neuroglial and innate neuroimmune system activation in the brain tissue and cerebrospinal fluid of ASD patients.

As a result of their findings, the authors recommended more study of neuroinflammation in the pathogenesis of autism. I'm quoting on those.

Despite increasing acknowledgment of and interest in the likely connection between neuroimmune issues and ASD, only three NIH-funded autism trials appear to address neuroimmune and neuroinflammatory issues: treatment with Donepezil HCL to increase cortical acetylcholine and control brain inflammation, a test of omega-3 fatty acids as an anti-inflammatory, and an immunological investigation of autism subtypes for children under seven.

So many of the current national priorities for ASD are focused on preventing and mitigating autism in the youngest population. Early detection and intervention and research to find the genetic-based susceptibilities for ASD will hopefully reduce populations of autistic children, but there is an invisible cohort of older children and young adults whose illness had a high probability of going undetected in infancy and, when detected later, interventional treatments were often limited due to availability of practitioners or personal and public budget constraints.

I believe we owe it to this almost forgotten cohort of older children and young adults to emphasize the need for safe, interventional, global, and immunomodulatory anti-inflammatory treatments, those that would have the highest likelihood of easing their illness.

I have three children, who are currently ages

10 to 14. All three have been diagnosed with varying degrees of autism, and yet all three children demonstrate blood markers indicating a CNS neuroimmune dysregulation. As a point of information, my spouse and I were diagnosed with autoimmune and chronic gastrointestinal illness, respectively, a few years before the children's autism diagnoses. This is definitely a familial condition for many of us.

There is a great need for fresh perspectives regarding the future direction and priorities of autism research as the IACC works to quantify the effectiveness and outcomes of innovative and newly developed intervention strategies by December 2010 in accordance with U.S. Code 42 Section 280I-3 of the Combatting Autism Act. I have a copy of the RFI I submitted associated with neuroimmune. Thank you for your time.

DR. INSEL: Thank you. The next name on the list I have is Joseph Mele.

[No response.]

DR. INSEL: I may be saying it wrong. "May-lay", Joseph Mele? M-e-l-e. No?

[No response.]

DR. INSEL: Katie Miller.

MS. MILLER: Dear members of the Committee, thank you for allowing me the opportunity to speak this afternoon. My name is Katie Miller, and I am here representing myself as an autistic member of society. I am pleased that so many resources are being directed toward the autism spectrum. However, there are a number of issues that I believe are important to express my views on.

Firstly, there is a strong need to improve and make available diagnostic services to a wider population. The number of mental health professionals sufficiently knowledgeable about autism spectrum disorders to properly diagnose and treat individuals on the spectrum is very small. Children have far more opportunities for diagnosis than adults do.

While knowledge of autism spectrum disorders is increasing, much of the information health professionals have is false. Others have wide gaps in their knowledge due to receiving medical training in an era when there was little knowledge of ASD. As I'm sure many of you know, many practicing psychologists, psychiatrists, and neurologists received their medical training before Asperger syndrome was added to the DSM in 1994.

Because scientific knowledge about autism is rapidly increasing, I propose research on how to give professionals the best possible information.

Secondly, please use funding to improve the quality of life for people on the autism spectrum, not to research a way that prevents more of us from existing. I am very concerned with the amount of funding supplied to research with eugenic applications.

If a prenatal test for autism is implemented, the autistic community fears that many parents would choose to abort fetuses who test positive. While I take no stand on abortion in general, this is of great concern to me because there can be no reliable way of knowing how happy a child may be in life simply by identifying certain genes.

I don't think it is necessary for me today to list the many contributions to mankind made by living autistic individuals, nor to list the numerous prominent historical figures suspected of having autism. I'm sure you have all heard those lists before. However, I would like to quote Temple Grandin. "After all, the really social people did not invent the first stone spear. It was probably invented by an Aspie who chipped away at rocks while the other people socialized around the campfire."

[Laughter.]

MS. MILLER: "Without autism traits, we might still be living in caves." She said that a number of times. This is quoted in her book Thinking in Pictures, page 122.

There are many ways to improve the quality of life for people on the autistic spectrum. One is better education and training of teachers and doctors so that proper treatment services can be provided to all individuals on the autism spectrum whether they are greatly or mildly affected by autism. Better assistive communication devices, social skills training, specialized schools, vocational training, specialized career and relationship counseling, and sensory integration therapy are other examples of services the autistic population needs throughout their lifetime.

Third, additional representatives who are on the autism spectrum should be placed on the IACC and in workgroups and other areas of research. Nothing about us without us. We are experts on our own autistic thoughts, ideas, experiences, and needs. No one else has that insight.

Fourth, I, as well as others both on and off the autism spectrum, are concerned about the continued presence of Alison Singer on the IACC. Her attitude toward autistic individuals and autism as evidenced in her comments in the film Autism Every Day indicates that perhaps the best interest of people with ASD are not being served by her membership on the IACC.

Like many in the autistic and autism communities, I was horrified and outraged while listening to her talk about almost killing her autistic daughter, Jody, in the Autism Speaks fundraising video Autism Every Day. Ms. Singer states on camera that she did not drive off the George Washington Bridge with Jody in the car only because of the fact that she has another child.

While the statement itself is derogatory, the most troubling aspect of the incident is that Jody is playing in the background.

I would like to conclude with the belief that many of the problems autistic people face are not due to autism but due to society's lack of understanding and tolerance for neurodiversity. Even the most severely affected so called low functioning individuals think intelligently, feel like all other humans, and many even make contributions to society.

I would like to see more attention spent on promoting an inclusive, tolerant society and less on trying to cure or eliminate those seen as defective. Thank you.

DR. INSEL: We had a discussion after our last meeting when another member of the public made comments directly about one of the members of the IACC. I guess it is fitting to go back to the value statements that we have talked about earlier today, in particular the one that talked about treating others with respect, listening to diverse views with open minds, and fostering discussions where participants can comfortably offer opposing opinions.

While I understand that there may be

differences of opinion about the film or about a statement made by a member of the IACC, I don't think it really is in the spirit of what we are trying to create here to single anyone out or to make this a less safe place for people who have come here with really very good intentions.

I hope that as we listen to public comments we also think about the consequences of things that we say. We recognize that everybody who sits on the IACC has feelings. They do this in their role today as public servants and we don't want anybody to feel like that in any way jeopardizes their ability to contribute.

I would just hope that as we go forward that people who make comments from the public show the same sensitivity to members of the IACC that we expect the IACC to show to each other.

The next person on the list is Ari Ne'eman.

MR. NE'EMAN: Thank you. Members of the Committee, thank you for this opportunity to give comment on the IACC's important work. My name is Ari Ne'eman. I am here today in my capacity as the president of the

Autistic Self-Advocacy Network, a nonprofit organization run by and for adults and youth on the autism spectrum. We work to encourage the increased representation of the autistic community in public policy deliberations about autism affairs.

I would like to take this opportunity to encourage additional autistic representation on the IACC and its workgroups, in keeping with the concept of nothing about us without us, a longtime pillar of the disability rights community that should be respected in autism policymaking just as it would be with the drafting of policy aimed at any other minority group.

In addition, we encourage this Committee to focus its research towards measures that will improve the opportunities for communication and quality for life of autistic individuals by funding research into augmentive and assistive communication, AAC technology, early and lifelong education and service delivery methods, areas of employment, independent living, housing, restraint reduction, positive behavioral supports, and other important spheres for autistic individuals everywhere.

I'm concerned by the fact that autistic people, family members, and others who make up ASN's international membership continue to face skepticism about the very existence of autistic adults. The media portrays the autism spectrum as something new, only existing amongst children, yet the adult population continues to lack needed support and awareness.

State voc rehab agencies and other aspects of the DD service delivery infrastructure are often ill informed about the needs of the adult population. Let me applaud the Committee on taking some initial steps to address that in its draft mission.

I was diagnosed on the autism spectrum at age 12, and I have been fortunate enough to benefit from a family that has been accepting of my differences and supportive of the educational services that have helped me to develop. Unfortunately, not all children on the spectrum are receiving that acceptance and support.

The current culture of despair and intolerance promoted in advertising by groups like Autism Speaks does not contribute to positive outcomes for autistic individuals. Statements that devalue autistic life, like those made by IACC member Alison Singer in the film

Autism Every Day, are of great concern to us primarily because they have an effect on the ground, so to speak.

I would like to add that my making a statement on this was done with great consideration, particularly after the discussion after my presence at the last meeting. I felt it necessary to continue to raise this issue after speaking with the family of an autistic girl who was killed shortly after the statements made in that fundraising video. They feel, and I feel, that the increased incidence of these horrible atrocities are related to the culture of despair and lack of hope that has been inadvertently promoted through the use of concerning fundraising tactics.

We hope that the IACC's language, and we see that there is progress towards that, does not reflect that.

Finally, genetic research surrounding prenatal tests for the autism spectrum is also a grave concern. It should be noted that researchers funded by Autism Speaks believe that a prenatal test for the autism spectrum could exist as early as 2015. There is evidence that such tests will and are leading to the use of selective abortion to engage in eugenics against the developmentally disabled.

It should be noted that approximately 90 percent of fetuses that test positive for Down's syndrome are aborted. While a prenatal test for the autism spectrum is significantly more complex to develop, once it is in existence the current climate of fear makes a similar result likely. We hold no position on the abortion debate in general, but we are deeply concerned by the emergence of eugenics in American society.

I consider it a grave human rights concern that many autistic individuals continue to be unable to communicate because the assistive communication technology and educational methodology research that could help many more adults and children convey their needs is being ignored in favor of eugenically oriented genetic research aimed at finding a cure for a natural and legitimate part of human genetic diversity.

DR. INSEL: Ari, we are pretty much out of time, so let's wrap up.

MR. NE'EMAN: Thank you for your time. We encourage the Committee to take the first steps towards shifting the main buzz word about autism from "cure" to "communication." Nothing about us without us.

DR. INSEL: Thank you. We have three more people on the list. We are coming up close to our adjournment time, so I want to make sure we keep the comments as brief as possible. Perry Olson.

[No response.]

DR. INSEL: That is very brief indeed. Alexander Plank.

MR. PLANK: Hi. My name is Alex Plank, and I was diagnosed with autism, specifically Asperger syndrome, at age nine. I'm here actually representing WrongPlanet.net, a website for people with autism which I started when I was in high school. There are over 17,000 registered members of the online community who have cumulatively posted more than 1 million messages about their experiences living on the autism spectrum.

It is troubling to continually hear members of my site's autistic community telling stories about difficulties they face on a day-to-day basis. Most of these problems are caused by a lack of public understanding of autism, the absence of any formalized support services in this country, and an egregiously low awareness of autism among medical professionals.

Professionals are not equipped with the tools they need to help those of us who are autistic, and most importantly, there is a lack of real understanding of the intellectual processes of autistic individuals.

Consequently, the focus of continuing research should be placed on that which affords autistic citizens a better quality of life. Autism organizations such as Cure Autism Now and Autism Speaks do not see this type of research as a priority. It is unfortunate that a large percentage of funding is going towards research that provides little to no benefit for the millions of Americans already living with autism, and I'm referring to research done with the goal of prenatal screening, a practice that would certainly discourage the many autistics who have been living fulfilling albeit challenging lives.

I would like to express that there is no reason to deem an autistic life any less valuable than another, especially when our intellectual capacity is in no way diminished. Many of us have performed in the top percentile of IQ tests, and a good number of us have provided valuable services to society. For instance, Nobel Laureate Vernon Smith is responsible for creating an entirely new field of economics, and he is diagnosed.

By mentioning these individuals I'm not trying to undermine the struggles faced by parents of individuals who are nonverbal. I hear about these struggles on my website every day. But even the parents who post about their nonverbal children acknowledge that their child's autism does not take away a son or daughter but only takes away the ability to communicate.

I'm going to refrain from criticizing members of the Committee because the problems we face are much bigger than the comments made by one parent. The forces that lead parents to dehumanize their children are systemic.

What kind of message does it send to the general public when the most financially significant autism organizations are running public service advertisements that continually employ emotionally charged, loaded, and misleading terms such as "disease" and "epidemic" in reference to autistic individuals such as myself.

You have to keep in mind that people like me make up an extremely large percentage of the one in 50. I think there is hope for everyone living on the spectrum.

I would like to conclude with a description about marketing professionals. Marketing guru Seth Godin explains that people and potential customers take action in response to three emotions: fear, hope, and love. He states that the easiest way to build a brand is to sell fear, especially during economic depressions. While fear may be an easy way to bring awareness, scientific studies resulting from this fear are inherently biased against the goal of increasing quality of life for autistics who are already living in this world.

In contrast, scientific research done out of hope has the potential to bring about a better quality of life for all of humanity.

I personally have the hope that the needs and perspectives of autistic individuals will be better represented by this Committee in the future. I thank you for allowing me to speak.

DR. INSEL: Thank you. The last name on the list is B. Sachau.

[No response.]

DR. INSEL: We are at 3:30, which is the time of adjournment. I think rather than taking any other public comments, as I said, we will post anything that we have received. There is also the opportunity to speak at the next meeting. I encourage people to send in their comments at least 10 days before the meeting.

I have two other quick things, just matters of business I want to make sure I clarify before we run our separate ways. One was, I believe that we heard from you that you wanted to have an additional meeting. Currently we are meeting in May and we are meeting again in November. We will have a meeting before May to get the workgroup together. But between May and November is six months.

My guesstimate of what I'm hearing based on this process is that we won't be finished in May. We may be very close. I'm wondering whether we should schedule a meeting in between May and November. I see heads nodding.

The other point is that you brought up today about getting the summary of scientific advances. We would like to do that. I just want to make sure that you are all okay with the Autism Team working with our Office of Science Policy and Communication to pull that together and to distribute.

Joyce, is there anything else you need?

DR. CHUNG: [Off mic.]

DR. INSEL: I again see heads nodding here as well. Any problems with either of those two things?

[No response.]

DR. INSEL: We will take those as both assents.

Listen, this is not the most pleasant day. I understand that there was just some hard stuff we had to get through here, but I appreciate everybody sticking with it. I think that we are still finding our legs a little bit in working together as a Committee. It is days like this that really help.

I appreciate everybody's willingness to

participate and stay engaged throughout the day. I suspect there are a few of you who thought that maybe you should take an earlier flight out of here, and I'm glad you didn't. So thanks for hanging in there with us.

This has been very helpful for us and for the Autism Team. I think we have a much clearer idea of how to move forward. We will look to you to get some nominations back for this workgroup. You will hear from us very quickly next week. We are going to get on the stick. I feel like we have lost a little bit of time here, but we are going to make it up going forward.

Thanks to everybody. We will look forward to seeing you at the very next opportunity.

[Whereupon, at 3:35 p.m., the meeting was adjourned.]