U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

TUESDAY, FEBRUARY 28, 2012

The Committee convened via teleconference at 2:00 p.m., Thomas Insel, Chair, presiding.

PARTICIPANTS:

THOMAS INSEL, M.D., *Chair*, National Institute of Mental Health (NIMH)

SUSAN DANIELS, Ph.D., *Executive Secretary*, Office of Autism Research Coordination (OARC), National Institute of Mental Health (NIMH)

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

JOSEPHINE BRIGGS, M.D., National Center for Complementary and Alternative Medicine (NCCAM)(representing Francis Collins, M.D.)

JUDITH COOPER, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD)(representing James Battey, M.D., Ph.D.)

GERALDINE DAWSON, Ph.D., Autism Speaks

PARTICIPANTS (continued):

LEE GROSSMAN, Advance Enterprises, LLC

ALAN GUTTMACHER, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)

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

LAURA KAVANAGH, M.P.P., Health Resources and Services Administration (HRSA)

WALTER KOROSHETZ, M.D., National Institute of Neurological Disorders and Stroke (NINDS)

CINDY LAWLER, Ph.D., National Institute of Environmental Health Sciences (NIEHS) (representing Linda Birnbaum, Ph.D.)

SHARON LEWIS, Administration on Children and Families (ACF)

CHRISTINE McKEE, J.D.

ARI NE'EMAN, Autistic Self Advocacy Network

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

DENISE RESNIK, Southwest Autism Research and Resource Center (SARRC)

CATHERINE RICE, Ph.D., Centers for Disease Control and Prevention (CDC) (representing Coleen Boyle, Ph.D.)

STEPHEN SHORE, Ed.D., Adelphi University and Autism Spectrum Consulting

ALISON SINGER, M.B.A., Autism Science Foundation

PARTICIPANTS (continued):

MARJORIE SOLOMON, Ph.D., M.B.A., University of
California, Davis and M.I.N.D. Institute

LARRY WEXLER, Ed.D., U.S. Department of
Education (representing Gail Houle, Ph.D.)

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PROCEEDINGS

2:04 p.m.

Operator: Thank you for standing by and welcome to today's conference. At this time, all participants are in a listen only mode.

Today's conference call is being recorded. If you have any objections, you may disconnect. I will now turn the call over to your conference host, Dr. Thomas Insel. Sir, you may begin.

Dr. Insel: Good, thank you. Welcome, everybody to a conference call meeting of the Interagency Autism Coordinating Committee.

And this was a meeting which we felt was overdue. It's been since September, actually since we've had a chance to hear from all of you.

So the agenda here is fairly loose. The main thing we wanted to do today, really we have three goals. The first is to give you an update on where we are with respect to the reauthorization and the new committee.

Second, and maybe the most important from our point of view is to hear from all of you about what's new since September so that we can make sure we are all in the loop and doing exactly what the IACC proposes to do, which is to coordinate between us, all of us.

And finally, there is some OARC business that we'll need to take care of, and we're going to ask Susan to help us walk through that.

So let's start by doing a quick roll call so those who are listening in will know who has joined the meeting. And I think the easiest way to do this, Susan, is for you just to read down the list so we can see who's here.

Dr. Daniels: Okay. So Linda Birnbaum or Cindy Lawler?

Dr. Lawler: Yes, this is Cindy. I'm representing Linda today.

Dr. Daniels: Thank you.

Dr. Insel: And that's from NIEHS, right?

Dr. Daniels: NIEHS. Ellen Blackwell?

Ms. Blackwell: Yes, I'm here. I'm with CMS.

Dr. Daniels: Henry Claypool?

(No response.)

Dr. Daniels: Josie Briggs?

Dr. Briggs: Hello.

Dr. Insel: Good.

Dr. Daniels: Hello. Judith Cooper?

Dr. Cooper: Yes, I'm here. NIDCD.

Dr. Daniels: Geri Dawson?

Dr. Dawson: Hi, I'm here, Autism Speaks.

Dr. Daniels: Lee Grossman?

Mr. Grossman: I'm here.

Dr. Daniels: Alan Guttmacher?

Dr. Guttmacher: Here from NICHD.

Dr. Daniels: Yvette Janvier?

Dr. Janvier: Present.

Dr. Daniels: Laura Kavanagh?

Ms. Kavanagh: Here from HRSA.

Dr. Daniels: Walter Koroshetz?

(No response.)

Dr. Daniels: Sharon Lewis?

Ms. Lewis: Here from ADD.

Dr. Daniels: Christine McKee?

Ms. McKee: Here.

Dr. Daniels: Ari Ne'eman?

Mr. Ne'eman: Here from the Autistic Self Advocacy Network.

Dr. Daniels: Lyn Redwood?

Ms. Redwood: Here.

Dr. Daniels: Denise Resnik?

Ms. Resnik: Here from the Southwest Autism Research and Resource Center.

Dr. Daniels: Cathy Rice?

Dr. Rice: Here from CDC.

Dr. Daniels: Stephen Shore?

Dr. Shore: Here.

Dr. Daniels: Alison Singer?

Ms. Singer: Here from the Autism

Science Foundation.

Dr. Daniels: Marjorie Solomon?

Dr. Solomon: Here from the M.I.N.D. Institute.

Dr. Daniels: And Larry Wexler?

Dr. Wexler: Here from the Department of Education.

Dr. Daniels: Great. And so Walter Koroshetz has not joined us yet. Henry Claypool has not joined us yet.

And I believe Gerry Fischbach and Larke Huang are not planning to join us. Anybody else that I've missed?

(No response.)

Dr. Daniels: Okay, then we're done.

Dr. Insel: Okay, that's great. Well, thanks to all of you for joining us. We've got a great turnout here. Let me say just a little bit by way of introduction about where we are.

A lot has happened since September. And what we want to do most of all today is to hear from all of you about what has changed and what we all need to know about.

I did want to start by addressing the elephant in the room which is the reauthorization. We were, as all of you know, reauthorized on September 30th of 2011, the very last day of the last fiscal year.

And that reauthorization, which was essentially what we would call a date and dollars act. That means that it didn't really change very much about the original Combating Autism Act except to extend what was in the original authorization and to put in additional dollars.

You have to always remember that the dollars that are in an authorization bill have really almost no impact on the dollars that any agency sees because dollars for agencies to function come only from appropriations, not authorizations.

So we have the new, the reauthorized CAA with us at this point. The other thing that happened at the same time was that the current committee was extended for the period that it would take to actually stand up the new committee.

So they've asked for a new IACC, but in the meantime we can meet as we're doing today, and we can continue to function as we have been functioning.

And that's given us, really, the wiggle room we've needed to keep things running and to maintain all the progress that we had made in the previous months and years.

We started off with a call for nominations that began on October 27th and ended on November 30th. And we had all of 107 responses. And that information was sent to Health and Human Services.

I think as all of you know, the membership for the IACC is, at least the public membership, is under the authority of the Secretary. So that's done by HHS, not by anybody who sits on the IACC.

So they have that entire package of 107 responses. And it includes the fact that also all the federal members need to be reappointed. And we will be in the process of doing that as well.

The fundamentals of how this works are pretty simple. The list gets put together as it has been. It's reviewed by the Office of the Secretary.

There are really two steps that go on from this point. There's a selection process where a group is selected based on the language in the bill, which is quite specific about where people need to be from and having each of several criteria met.

And then there's, after a selection process, there's an actual appointment process, which involves some vetting because the appointment requires, or the service on the committee requires being what's called a special government employee, or an SGE.

And SGEs have to go through, just

like any other government employee, a certain amount of ethics clearance and other kinds of clearances to be able to serve. That can take some time.

So at this point, we actually do not have the slate, so I can't tell you who's on, who's off. As I mentioned, that really is under the domain of the Office of the Secretary and we're eagerly awaiting some notice about the appointments being under way.

I should mention that once the appointments are made, that's considered to be confidential information until we actually have approval of everyone from this process right through the special government employee vetting process.

So this is taking longer than we would have liked. We were eager to get this process wrapped up fairly quickly so that we could move forward with an official meeting of the new committee.

But we have got to go through the

process as we've got it. And at this point I think we would have to say that we will not be having a meeting in the near future, at least in the next few weeks because it is going to take longer to get through both selections and appointments.

Susan, do you want to add anything to this because you've been more involved?

Dr. Daniels: I think that you've covered it pretty well. So we are awaiting the selections and then the members who are selected will receive packets of paperwork that will have to be returned to us.

And then we'll go through the appointment process. So we'll be able to get a better sense once we know the selectees.

Dr. Insel: Questions from any of you?

(No response.)

Dr. Insel: Okay. We will let you know as we hear more about what the expectation is.

And I think many of you know that if you serve on the committee currently and you were renominated and you were able to renominate yourself, and in some cases you did that, those packages have gone forward.

So we really now have to see how this plays out in the Office of the Secretary.

The only other thing I wanted to mention by way of getting everybody up to date, as I said, there's a lot that has happened. October was a big month for autism on the research side with a special satellite symposium sponsored by Cell Press at the Society for Neuroscience meeting.

And just an enormous amount of activity at the Neuroscience meeting. I think there were 26 independent talks and over 92 posters around autism at this year's meeting as well as the cover story in the issue of ***Nature*** that came out during the meeting.

So a lot of activity at that point. There have been a number of things that have happened since then that I'll go back to those when we go around the table and do updates from each of the different components of the IACC.

Susan, anything more in terms of updates from OARC or anything else to mention at this point before we move right along into the member updates?

Dr. Daniels: I don't think so. I can do my update after everyone else is finished.

Dr. Insel: Okay. So if that's the case, why don't we go right ahead and the main item on the agenda was really just to get everybody up to speed on what's been happening in their own organizations.

So if you don't mind, Susan, if you can go ahead and just take us through the list and --

Dr. Daniels: Sure.

Dr. Insel: -- we'll give people each a few minutes to talk to the rest of the committee about what they've been up to.

Dr. Daniels: Okay, do we have an update from Cindy Lawler, NIEHS?

Dr. Lawler: Yes, I have a meeting update I wanted to share with the committee. This is a meeting NIEHS worked with Autism Speaks to organize.

It was late last year, entitled Bioinformatics and Computational Approaches to Integrate Genes and Environment in Autism Research. It was held November 29th and 30th in Research Triangle Park. We brought together experts in bioinformatics, computational and small molecule screening paradigms, with key researchers in genetics and neurobiology of autism.

And the primary goal of the meeting was to discuss possibilities for how new bioinformatics and approaches could be used to advance research on the environmental contributors to autism.

And we were very grateful that the Office of Autism Research Coordination at

Mental Health provided webcasting for the event.

And this particular meeting met an objective under question three in the IACC 2011 Strategic Plan for Autism Research. I am putting together, pulling together the meeting report and specific recommendations.

And those should be available in the next few weeks. And I'll make sure there's a link posted on the IACC website to help schools who might be interested in accessing that report.

Dr. Insel: Cindy, before you go on, if it was webcast, is that archived someplace so that if somebody didn't attend the meeting, they would be able to watch the webcast?

Dr. Lawler: Susan, can you comment on that?

Dr. Daniels: Yes, that information, you should be able to access the webcast off the IACC website if you go into non-IACC meetings.

Dr. Insel: Okay.

Dr. Daniels: And it should be listed there.

Dr. Lawler: Thank you.

Dr. Insel: Anything else from NIEHS?

Dr. Lawler: Well, we're in the midst of a strategic planning meeting, but I don't have any specifics to share. We're, you know, moving ahead, identifying our new priorities.

And I think, you know, a lot of what we've been supporting in the field of autism will be very well aligned with our new directions.

Dr. Insel: Okay. Thank you.

Dr. Daniels: And Cindy, the neurotox meeting, did you want to say anything about that?

Dr. Lawler: Oh, yes. There was an international neurotoxicology meeting that was held in Research Triangle Park, as well.

And one of the foci of the meeting this year was trying to understand how endocrine disruptors may have relevance for neurodevelopmental disorders. And that would include autism, ADHD and schizophrenia as well. So there were a couple sessions that were really trying to just set the stage.

And, you know, with information that we know currently about mechanisms of action, of endocrine disruptors, trying to align that with how that might be relevant to the pathobiology and etiology of those disorders that I described.

But it was very well attended. I know Susan and a few other folks from NIH were able to attend as well. And a nice thing about that meeting is, the meeting proceedings are published. And so the reports for that should be available in the next few months. It's published in the journal of ***NeuroToxicology***.

Dr. Daniels: Great. And Cindy, I'll just add on, OARC also co-sponsored a webinar, or I mean, a webcast for that. And it's available on the same site I just mentioned, on the IACC website. If you go into non-IACC meetings, you can watch a webcast of the autism portion.

So then we'll move on, next, thank you so much, Cindy, to Ellen Blackwell from CMS.

Ms. Blackwell: Hi. I just wanted to mention, because there's been a lot of interest in the autism community that, on December 16th, the Department released a preliminary bulletin on guidance associated with the essential health benefits package that will be part of the health reform law in 2014. And, you know, there is some really good guidance on the CMS website. One of our components is actually in charge of developing this benefit.

And the Secretary has decided to take a benchmark approach, which is similar to coverage that CMS offers in the CHIP program and also in the Medicaid program.

Specifically one of the ten targeted categories in the law is Number 7, rehabilitative and habilitative services and devices. So according to the memorandum, states have a lot of flexibility in terms of which benchmark they elect to adopt.

And I think that there are still a lot of issues that will need to be resolved, in particular, surrounding, you know, the coverage of certain benefits including early intervention services for people with autism.

So, you know, I guess we just have to stand by and really see what happens as states come in with their benefit packages over the next few months.

Dr. Daniels: Great, thanks, Ellen. Do you have additional items?

Ms. Blackwell: No, that's it for today.

Dr. Daniels: Okay, thank you.

Dr. Insel: If people have

questions, you shouldn't be shy, because this is really meant, and even though we're not in the same room, we're hoping that this will be a discussion.

Dr. Daniels: Okay, so do we have Henry Claypool on the line or anybody from Office on Disability?

(No response.)

Dr. Daniels: I'm not hearing anyone. Any update from the NIH Office of the Director? Dr. Briggs?

Dr. Briggs: I don't think so.

Dr. Daniels: Okay. Judith Cooper from NIDCD, do you have an update?

Dr. Cooper: No. A lot of the NIH folks are preparing for the review of the ACE centers and those applications. And I imagine that after these all go to council, we'll have a report for the IACC about the outcome of that.

Dr. Daniels: Can you mention just briefly what the ACEs are for anybody who might be new to the committee that doesn't know?

Dr. Cooper: Well, ACEs stands for Autism Centers of Excellence. And we've supported these for, this is our second time. Oh well, our first -- they have been supported for the last five years.

They are either centers that involve several projects on a particular theme related to autism, or they are clinical trials. Networks of various sites focused on a particular problem.

Dr. Daniels: Great. Thank you.

Dr. Cooper: Sure.

Dr. Daniels: Geri Dawson? Autism Speaks.

Dr. Dawson: Hi, everyone. Just a few things, briefly. We sponsored a conference, I think it's the first conference on epigenetics and autism.

And this brought together experts from other diseases and conditions that have examined epigenetics, and also autism researchers.

Out of this conference, there's now been established two networks of investigators who are working together to develop a research agenda and proposals that are focusing on epigenetics.

In addition, we funded a major project on epigenetics and autism that builds on the CDC SEED study and utilizes those resources.

I also wanted to mention that Autism Speaks established a formal collaboration with the Beijing Genome Institute in which we're seeking to conduct whole-genome sequencing on all of the 10,000 samples that are part of the Autism Genetic Resource Exchange.

And we're well into that project and making really good progress. So we hope that within a period of two years, that we would be able to provide a really great resource to the community of investigators exploring genetics.

I also wanted to mention that we

have been working with the Simons Foundation, and some folks from industry, and many academic experts to develop consensus on outcome measures for clinical trials.

So we have two working groups that have been meeting once a month over the past year and have been reviewing, doing a very systematic review of all of the outcome measures in the areas of social communication deficits, restricted and repetitive behaviors and anxiety.

And developed criteria for understanding, or for evaluating each one of those outcome measures and then developing a set of gold standard measures that there's consensus on.

On March 23rd, we will be having a meeting in Washington D.C. that will involve the NIMH, people from the community, academic experts, and Autism Speaks and the FDA to review the progress that we've made in developing consensus around outcome measures, as well as develop a kind of forward-looking research plan on what are the gaps that are needed in this area.

And then, finally, I wanted to mention that we, as part of a major initiative on adults with autism that is part of Autism Speaks' overall strategic plan.

We held a summit on research on adults with autism in January that involved several keynote speakers including Marsha Malick Seltzer and Paul Shattuck. And the topics were trajectories of development in adolescents and adults, novel approaches to diagnosis and intervention, service use and outcomes, and then factors related to optimal outcomes in adulthood.

And all of the meetings have either already been provided by webinar, or they were videotaped and we're in the process of getting those onto the web. So they should be accessible.

But if anyone is interested in any

of those meetings, please email me and I can provide you with some more detail about them.

Dr. Insel: Geri, this is Tom. Do you want to say something about the project around biomarkers and -- because the Simons Foundation isn't going to be on this call, I don't think. So it's up to either you or me.

Dr. Dawson: Absolutely, sure. And so another collaboration and effort that is under way right now is what's called a biomarkers consortium.

And there's many people involved in this including five pharmaceutical companies or biotechs from industry as well as the Simons Foundation, several representatives from NIH and also the Foundation for NIH and Autism Speaks, with the idea of trying to develop a collaborative project that would help accelerate the discovery and validation of biomarkers.

And in particular, there is a great interest in developing measures that could provide an early readout of response to intervention.

So when one conducts a clinical trial, it's extremely helpful to have a measure that could very rapidly determine whether that particular treatment is causing a change in whatever process that you're interested in changing.

And so there will be a meeting in the near future, I think it's, I'm trying to remember. Is it April or March? It's on my calendar. Tom, you may know because I know you're coming.

And I could certainly email people with the information. But there will be a meeting, I think it's, do you know the date, Tom?

I'm sorry, I just don't have it in front of me. I could certainly email it to you by the end of the meeting today.

Dr. Insel: I think it's March 28th, 29th. Does that sound right?

Dr. Dawson: Yes, I think that does sound right. So the end of March. And the purpose of that meeting, again, will be to bring together representatives from industry and the Simons Foundation, Autism Speaks, FNIH and NIH to develop this collaborative project on biomarkers, which is going to be very critical in terms of making progress in the area of medicines development.

Dr. Insel: Great. Okay, thank you.

Dr. Daniels: Thanks, Geri. I think Gerry Fischbach isn't on the call. Lee Grossman?

Mr. Grossman: Hello?

Dr. Daniels: Hello, do you have an update for us, please?

Mr. Grossman: Yes. Sorry, I had to take my phone off of mute. Yes, I've been very active with a number of organizations, consulting with them.

These are for-profit organizations that have either a product or service for disabilities or autism. I've been working with them on their business development and strategic planning.

Really the one update that I'm at liberty to provide now is that with one of the groups that I'm working with, we have 15 conferences planned throughout North America for this year.

And we're about to finalize the venue and dates for one of those conferences, which will be in Washington, D.C. It will be a two day conference, May 31st and June 1st.

And many of you will be hearing about it and receiving invitations to speak. It's going to be a two-day conference entitled, loosely titled at this point, Autism Through the Lifespan.

And we think it will be a very good event. I think the speakers that we're going to be bringing in will have the latest in information on what's happening in autism on the service and support side.

And as I said, some of you will be receiving invitations to present there, as well. And if you could circle your calendars on there.

Not at liberty to say more than that at this point, since papers are going back and forth to finalize the venue and the dates. And we're supposed to be signing off on everything in two days, on Thursday.

But it's good hearing these other updates. I appreciate it, and all the hard work that everybody's doing for the autism community. And keep it going.

Dr. Daniels: Thank you, Lee. Alan, do you have an update for us from NICHD?

Dr. Guttmacher: No, this is actually from NIH in general, and there are other people on the call who are probably more expert about this.

But just to call people's attention to a funding opportunity announcement that was released at the end of January having to do with the Health Care System's Research Collaboratory program.

And in it, specifically, it includes studies to examine the best strategies and impact of early screening and identification of children with autism spectrum disorders.

So if folks are interested in looking at that in more detail, it's on NIH website, the number is RFA-RM-12-002.

So just calling people's attention to that, as I recall, I think April due date. And I think that's about it from NICHD.

Dr. Daniels: And Tom, do you have more to add to that?

Dr. Insel: Yes, let me just do a bit of a, this is Tom, a couple of NIH-wide updates. As I think as most of you know, we actually got a budget this year.

On December 23rd, the FY12 budget was approved. That keeps us pretty much flat with FY11.

And the FY11 budget for autism was

around $169 million, which is up a little bit from the budget in FY10 of about 160, not counting the money that went into the ARRA money.

The FY13 President's budget was released a couple of weeks ago. And as I think, those of you who follow these things know that that looks a lot like the FY12.

And you also probably know that the President's budget is, as a proposal it really depends, because our appropriations come entirely from Congress, it depends on what happens when that hits Congress.

The expectation is that there will be a lot of discussion. It's an election year. That budget also will not be approved or finalized before the beginning of the next fiscal year, which is October 1st.

One of the things that did happen with the approval of the FY12 budget was the formation of a new center at NIH. The first such new institute or center since 2000.

So it's kind of an important landmark for the NIH. This is called the National Center for Advancing Translational Science (NCATS). And Josie Briggs, who's on the call, and I are both very heavily involved in it.

It's relevance to autism is that part of what this center will be doing is managing the 60 clinical translational science awards that are around the country and are supporting translational science throughout the country.

About nearly a half billion dollar program to do that. And pediatrics is heavily represented there. So autism does have a home there.

But maybe even more relevant for our discussion here is that this new center, NCATS, has got a very heavy focus on rare diseases.

And of course, what we call autism includes a number of rare diseases, Fragile X, Timothy Syndrome, tuberous sclerosis, you can go down the list.

And this will be a place where some of the rare-disease research will both be coordinated and potentially even supported, especially with a focus on developing new therapeutics, and in some ways, re-engineering the pipeline to develop new therapeutics. So something to watch. There is an NCATS website up and you're welcome to take a look at that and begin to see where the opportunities may develop for the autism community.

The other things to just mention that have happened over the last few months, just to give you a quick update on NDAR, National Database for Autism Research has had a very active period here.

I think some of you may know that in October, it received one of the HHS Innovates Awards. They give three a year.

This was a great moment, really a way to sort of focus on innovation within the federal government, and we were immensely proud to have NDAR recognized in this way.

The database itself has grown. We're up to 25,000 subjects and about 170,000 records, and much of the last few months have been focused on the federation with IAN and AGRE, that's the Interactive Autism Network that was originally developed through Autism Speaks. And AGRE is the Autism Genetics Resource Exchange, which Geri mentioned a moment ago, which was originally developed through CAN, and then later, Autism Speaks.

And so these are large efforts. When the three repositories are fully integrated, which we think they'll be in the next several days, we'll be up to 38,000 total subjects and it will then be, I think, a real workhorse for the whole field.

One of the things that's happening, even before we had expected it is that we're beginning to see papers that are describing results from the first round of the ACE awardees that are actually bringing in the NDAR data.

They weren't actually required to share data into NDAR until after publication. But this is happening just as the publications occur or in some cases even before. So that's great to see.

And one final mention about NDAR is that there's a terrific video made, some of you are in it, about the importance of data-sharing and using NDAR that will soon be on the website for NDAR as well.

So keep an eye out for what's happening at NDAR. We do think it's going to be a great resource for the entire field.

Within the NIMH focus particularly, a couple of things to mention. Geri already mentioned the biomarkers effort, which is under way.

We've also jumped the gun on that a little bit by putting out a solicitation for a new contract.

It's called a Fast Autism Spectrum,

or Fast AS contract, which is going to be funding experimental medicine trials or early-stage target validation trials for potential new therapeutics.

And I would refer anybody who's interested in this to the NIMH website. You can simply Google or search for Fast-AS and it will take you to the RFP for this.

The submission deadline is March 21st. And the hope is to move very quickly, again, in line with the request from the IACC strategic plan to really begin testing out new therapeutics and to begin, most importantly, testing out new approaches to target identification and target validation for autism.

So that is something to watch out for and it's an area that we think there will be a lot of excitement in.

Finally, there's been a fair amount of congressional interest that continues around autism. We did a briefing for Congressman

Sherrod Brown from Ohio. His district covers most of Cleveland. And that was done in mid-December with some constituents from his district.

Chris Smith, who I think all of you know about because he co-sponsored the reauthorization of the CAA, will be coming out to NIH next week and will be spending some time on our autism unit and our intramural program at the clinical center here in Bethesda.

So we're looking forward to that as well. That's a quick run-down. If there are any questions, happy to unpack any of that further. Okay.

Dr. Daniels: All right. Well, the next person I have on the list is Yvette Janvier. Do you have any comments or updates for us?

Dr. Janvier: You know, as some of you know, I'm primarily a clinician, but I am working on a grant looking at children, identifying them in under-served communities.

And we will be presenting some of our findings at IMFAR. Things have been accepted.

But the somewhat scary thing is we, in our population of close to 900 children, we're finding about a three percent incidence of autism in New Jersey populations of primarily African-American and Hispanic children.

So more to follow, and we will be at IMFAR.

Dr. Insel: Some of you may have heard the NPR story this morning from Rebecca Landa's work on the later identification of autism in African-American children.

Dr. Daniels: Thank you, Yvette. Laura, do you have an update for us?

Ms. Kavanagh: I do, indeed. This is Laura Kavanagh from HRSA. We funded, recently in September through our Autism Intervention Research (AIR) Awards, three secondary data analysis grants and five multiyear R40 grants totaling $1.8 million.

So the whole research portfolio now includes 17 R40 grants, eight secondary data analysis grants and three research networks.

We are also now funding 43 Leadership, Education and Neurodevelopmental Disabilities, or LEND, interdisciplinary training programs, these are targeted to health professionals throughout the country, and 13 state demonstration grants. All the details about the topics of the research investments and the interdisciplinary training programs are available on our website, www.mchb.hrsa.gov/autism.

We continue to partner with CDC, the LEND programs and others on the “Learn the Signs, Act Early.” campaign, particularly most recently around the ambassador's program that I'm sure you'll hear more about from CDC.

And there are two Autism Awareness Month activities that will be open to the public that we want to make sure you're aware of.

There will be a research webinar on autism cluster analysis where Dr. Traci Clemons from the Autism Intervention Research Network on Physical Health will be presenting. That's April 23rd from 3:00 to 4:15 Eastern Time.

And there also will be a webinar about HRSA's investments, what's been the impact on states, families and health professionals.

And that webinar will be held on April 25th from 1:00 to 2:30 p.m. Eastern. And that's it from HRSA.

Dr. Daniels: Great, thank you, Laura. And when you have these webinars coming up, if you want to email OARC about them, we can place them on our website in the non-IACC meeting section. And that goes for anybody else who's on the committee who's hosting something that's open to the public. We would be happy to post those meetings up on our website.

Ms. Kavanagh: Great, I'll send that to you.

Dr. Daniels: Walter Koroshetz?

Dr. Koroshetz: Hi, yes, from NINDS. A couple of brief things. So our budget as calculated by the NIH RCDC system is about 21.3 million for autism in 2011, which is up from 2010.

Much of the research that we fund is looking at things like brain imaging, connectivity and as it relates to language processing. Looking at biomarkers in terms of pupillary light reflex as a marker of potential risk for autism.

We are funding a large Norwegian cohort of mothers and their infants looking for clinical, environmental or genetic markers that predict autism coming on later in life in these children.

And also there's a major emphasis to look and see if there's biomarkers in the cord blood or the mother's blood that would predict autism coming on.

And we also do quite a bit of research, as Tom mentioned, in a number of the rare disorders with autism that are on the autism spectrum like Fragile X, Rett Syndrome, tuberous sclerosis. And there's lots of advances in those areas now.

And finally, I would just like to mention that we're planning, finally, a workshop on epilepsy and autism for late May. We're working with the Citizens United for Research in Epilepsy and Autism Speaks, and NICHD.

So, I know we've talked about this on a number of occasions and hopefully this will be a springboard to get things moving a little bit faster. So that's it from NINDS. Thanks.

Dr. Daniels: Thank you, Walter. Sharon Lewis, do you have an update?

Ms. Lewis: Sure. As several other of our colleagues have talked about, since we haven't met since last fall, ADD did award our discretionary funds last September, since we've last met, including six demonstration grants to states looking at partnerships in employment, specifically targeting youth and young adults.

These are collaborative efforts across the departments of education, DD service agencies, vocational rehabilitation and DD councils and university centers in most states.

And we have more information about those awards on our website. But those are five year grants with a fairly substantial amount of resource invested in those. And we're very excited about the opportunities related to employment.

We also funded two secondary data projects that may be of interest to the IACC. One is the expansion of the National Core Indicators, which has been an ongoing project of the National Association of State Directors of Developmental Disability Services.

That's currently in about half the

states. And this project really looks at quality of life indicators from a variety of perspectives including individual outcomes, health welfare and rights, around things like safety and personal security, health and wellness, and protection of individual rights.

As well as system performance issues related to service coordination, family and individual participation in decision making, and utilization and outlays for various types of services.

So that award was set up with the goal of getting the NCI into all 50 states within a five year period and expanding that database.

Our other national secondary data project that we funded this past fall is a project focused on looking at supporting families.

And the whole issue of supports to families in which an individual with an intellectual or developmental disability is living and building on our other longitudinal data projects to really focus on the distinction between services and supports that are targeted to families versus services and supports that are coming into the home for the individual that the family benefits from and really beginning to carve out that distinction.

The other thing that I wanted to just mention is we're partnering with the Department of Education as well as the Department of Labor and Social Security Administration in getting ready for the National Transition Conference which will be May 30th, 31st and June 1st.

Looking at both the perspective of employment, education and social services needs of youth with disabilities broadly, all the youths with disabilities, not specific to autism.

And we anticipate a call for papers and speakers any day now out of that effort. And when we have that information, we will certainly share it with the IACC members.

And last but certainly not least, we participated in a recent meeting with Autism Speaks as well as a collaborative of community colleges who are interested in post-secondary opportunities for students with autism.

And are working with the Department of Education Under Secretary Martha Kanter's office in ensuring that those opportunities that currently exist in federal law and federal financial aid are well known to the community and that the data and research in supporting the current fledgling efforts for demonstration projects continue.

ADD continues to fund the Think College effort as does the Department of Education in really looking at those post-secondary programs.

Dr. Daniels: Thank you, Sharon. Do we have an update from Christine McKee?

Ms. McKee: Hi, Susan. I don't have an update. But I wanted to mention a recent development in the area of seclusion and restraint that's getting a lot of parental and internet attention.

And it's this Connecticut investigation. In January of this year there were complaints filed with the state and federal agencies over time out rooms that have been used in elementary schools there.

These are four by six cinder block rooms that are used to isolate children that are having disruptive behaviors. It looked like the complaint was filed on a differential treatment basis.

You know, children with disabilities were being placed in these rooms as opposed to neurotypical children.

I don't know if the investigation's going to be broader than that, if they're just going to hit on the differential treatment issue.

Or whether it's going to get around to the issues that we spent talking about at our services workshop and in our letter to the secretary about, you know, there being no therapeutic validity to this kind of treatment.

And that positive behavioral supports are much more effective. I don't know if anyone on the phone, I don't know if Sharon or anyone from the Department of Education can comment on this or give any more information.

I'm just interested, there is a lot of parental concern out there about seclusion and restraint issues and we continue to have problems legislatively pushing things forward.

So maybe it's going to happen through the judiciary, I don't know. But just wanted to bring that to everyone's attention and see if anyone had any information that they could share.

Mr. Ne'eman: I would be very interested in hearing more about that. Would it be possible for you to email the committee with additional information on that case?

Ms. McKee: Ari, what I have comes,

I mean, from the internet and I'm happy to give you the sites. You know, I don't have a hard copy of the complaint.

It looked like the U.S. Office of Civil Rights within the U.S. Department of Education. I don't know if they were taking the lead, because other articles talk about state officials.

So I'm not sure whether the state or the federal agencies are taking the lead in the investigation. But the parental accounts throughout the internet stories are pretty frightening.

But I'll forward the links to you that I have and what I've read.

Ms. Singer: This is Alison. Susan, I was wondering if during your OARC report later, you'll be updating us on the letter that the safety committee sent to the secretary with regard to restraint and seclusion?

Dr. Daniels: I didn't have that planned because there really isn't a lot to update you on. But I'll make a point to mention it.

Ms. Singer: So she did not respond to the letter?

Dr. Daniels: We have not received a response.

Ms. Singer: Okay.

Dr. Insel: Anything else in response to Christine's comment?

(No response)

Dr. Insel: Okay.

Dr. Daniels: All right. So the next person on the list is Ari Ne'eman. Do you have an update for us, Ari?

Mr. Ne'eman: Yes, a few updates, actually. First, this past December, we partnered with the Harvard Law School Project on Disability and the Petrie-Flom Bioethics Center with support from the Administration on Developmental Disabilities to hold a symposium on ethical, legal and social issues in autism research as a way of continuing the conversation that began with NIH's symposium in September on a similar topic.

Many of you on the call, I think, were in attendance including Sharon and Alan and others. And it was a great success.

Among the topics we discussed were issues of safety and self-determination and service provision, both residential and otherwise, appropriate intervention goals across various educational methodologies, prenatal testing, community participation and research, community based participatory research methodologies and a wide variety of others.

It was telecast. We are currently in the process of putting up the webcast online. It's been somewhat delayed because we wanted to make sure it was captioned before it was posted.

But it should be make available in the next few weeks. I'll make sure that the links go out to the full committee.

And we're going to be following up on the symposium with a series of policy briefs exploring various ELSI issues in the context of autism and developmental disability research.

Dr. Daniels: Thanks, Ari. Do you have additional items?

Mr. Ne'eman: Yes. One additional one. I'm pleased to announce that we are going to be holding a week-long advocacy training for college students on the autism spectrum this August, from August 12th through 17th.

And we've recently circulated an application for participants for that. The application is due March 30th. And there seems to be a lot of interest in the community.

We're hoping to utilize this as a mechanism to build more opportunities for shared advocacy and autistic culture in the higher education sphere.

Dr. Daniels: Great, thank you.

Dr. Solomon: Ari, this is Marjorie. I was just wondering if you could talk a little bit more about the focus of the advocacy? Will it be managing school life; will it be managing just community life or vocational opportunities?

Mr. Ne'eman: Absolutely, Marjorie. So last year, we released a handbook entitled Navigating College, which consisted of articles written by autistic college students with practical advice on some of the issues you just described with regards to individual self-advocacies.

Everything ranging from getting the right accommodations in the classroom, dealing with issues which may emerge in residential life, dealing with extracurricular and social environments of the college environment, relationships and sexuality, safety issues and so on.

This training has a somewhat different focus. It's oriented more around collective self-advocacy.

So the objective is going to be to

help prepare these students to be change agents on their campus through advocacy and activism.

So, you know, we're trying to move forward on both tracks. Both the things that relate to individual's day-to-day experiences and some of the more political and policy oriented advocacy activities.

Dr. Solomon: Thanks.

Mr. Ne'eman: Sure.

Dr. Daniels: Any other comments?

(No response)

Dr. Daniels: Do we have an update from Lyn Redwood?

Ms. Redwood: Hi, yes. I just wanted to mention that SafeMinds was a platinum level sponsor of the recent neurotoxicology conference that Cindy mentioned earlier.

The focus of the conference was on environmentally triggered neurodevelopmental disorders with a focus on autism, ADD, ADHD and schizophrenia.

We were instrumental in planning the

plenary session which specifically addressed endocrine disruption in autism.

We've also been working actively with the United Nations Environmental Program on the development of a global treaty to reduce mercury pollution.

And we've attended several of the negotiating sessions that occurred in Chiba, Japan, and most recently in January in Nairobi.

SafeMinds also created an educational campaign which was targeted at OB/GYN doctors in an effort to decrease mercury exposure prenatally from environmental, dietary and medicinal sources of mercury from influenza vaccine which is recommended during pregnancy.

More than half of all the influenza vaccine manufactured today still contains 25 micrograms of ethyl mercury.

So we created DVD's, posters, educational brochures in an effort to reduce some of these exposures.

There was also research just

published by Harvard researchers that was funded by SafeMinds and the journal ***Cerebellum*** that reported that maternal thimerosal exposure resulted in aberrant cerebellar oxidative stress.

Also thyroid hormone metabolism levels were aberrant along with motor behaviors, and this was in rat pops. And these abnormalities were both sex and strain dependent.

This research was also presented at the neurotoxicology conference. And we're currently following up on research that just reported that an ancestry of pink's disease was a risk factor for ASD.

And this research was out of Australia where they conducted a survey of 502 adult survivors of pink's disease.

Pink's disease was very prevalent in the early 1900's and it was linked to exposure to mercury from teething powders.

And what they found was that in the

grandchildren of these pink's disease survivors, the prevalence of autism was one in every 22, which was significantly higher than the prevalence rate in Australia, which was one in every 160.

So we're hoping that this research may help to identify some heritable risk factors for the development of ASD. And that's it.

Dr. Daniels: Thank you, Lyn. Do we have an update from Denise Resnik?

Ms. Resnik: Yes. Just two weeks ago, we opened our Sanders Center for Autism Studies, which is 10,000 square feet and co-located with our vocational and life skills academy.

And we're excited about what that means in terms of being able to advance research with our young adults and adults on the spectrum.

We have served as a robust site for the recruitment and enrollment of subjects in pharmaceutical trials, and right now we have, I believe four underway.

And also research on our clinical programs. And in our vocational and life skills academy, we currently have about 225 teens engaged in different programs.

And about 200 adults with autism involved in our vocational academy. And I'm very proud to share that 85 of those adults are gainfully employed.

And we are working with advancing futures on adults with autism to continue advancing the concerns of adults as it relates to employment, residential and community life.

Just two weeks ago, we also hosted the leadership council meeting for AFAA, which today represents 12 national autism organizations and is continuing to grow.

We're also working on plans for our residential model, which we hope to break ground on next year.

And are learning from many other

organizations across the country including NARPAA and we attended last week the National Association of Residential Providers for Adults with Autism conference in Las Vegas.

And I believe we have a new model that we can introduce which represents public/private non-profit collaboration. And we'll certainly help make a greater dent in the needs for adults with ever increasing numbers.

Our clinical trials underway right now are with Forest Research Institute and Seaside Therapeutics.

We're also working with Novartis and Roche and then continue with our recruitment on our molecular and genetic studies, and are proud to be one of the largest contributors to the autism genetic resource exchange.

Just got our numbers in for 2011, and last year alone we worked with and served 1,200 children, youth and adults, 5,000 family members through education and training, and 3,700 education and medical professionals.

And so for SARRC, we are continuing to fulfill this mission of advancing discoveries and serving individuals with autism and their families throughout their lifetimes.

And we are going to be hosting our annual community breakfast April 19th. We had the pleasure and privilege of having Tom Insel join us last year for that breakfast.

And I invite any and all of you to join us and to tour our two facilities. As I mentioned, the Sanders Center, and also our 18,000 square foot Campus for Exceptional Children.

And what is truly remarkable about, I think, SARRCs activities is that even though, you know, we have maybe 28,000 square feet, which is not insignificant, it's truly what happens throughout the community through employers, through non-profits, through our schools.

And I might add, it's not just in Arizona. Late last year, we also received a contract from the State of Hawaii to help with their educators in making sure that they were advancing best practices in their schools in Hawaii.

And we are continuing to consult with schools across the country and in Canada. So if you can join us April 19th, please let me know.

Dr. Insel: Okay, thank you.

Dr. Daniels: Thanks, Denise. Cathy, do you have an update from CDC?

Dr. Rice: Hi, everybody. Sure. So CDC's Autism and Developmental Disabilities Monitoring network, or the ADDM network which has provided prevalence estimates for autism in the past will be releasing a new prevalence report this spring.

And we'll be working with partners to conduct outreach about these new prevalence findings when they are available.

Also, last year we had reported on a workshop we co-hosted with Autism Speaks on understanding ASD trends. And it was a forum to share ideas to move the community forward to better understand the ASD trends.

There were several excellent ideas that were shared during that workshop. And we've followed up on some of these including a publication that looked at a mathematical model for estimating the impact of certain pregnancy and birth factors on changes in the ASD prevalence.

We've also partnered with Autism Speaks, who is funding a direct screening and assessment component in the South Carolina ADDM site to look at completeness of prevalence estimates in that site.

In addition, we work with several of the folks on the call, including NIH, Autism Speaks, and the University of Minnesota has been funded through the Association of University Centers on Disabilities to study autism in the Minnesota Somali community.

That project is underway with IRB

proposals approved. The research and community teams have been hired and trained with community outreach certainly in process right now, and collaboration with the school system to begin looking at passive consent for individuals to participate in that.

So those surveillance activities will continue, hopefully with an update as the year progresses.

In terms of our research activities, the Study to Explore Early Development, there was a first report from this study. Was it a methods paper that was published in the Journal of Autism and Developmental Disorders in February?

So this is an outlining of the methods. Currently there are initial analyses underway looking at describing the children. Looking at also demographics and additional analyses that will be published next year.

Other analyses, looking at things such as maternal medication use, infections, lifestyle factors and interactions with genes are being planned and underway as well.

So we also initiated Phase 2 of the SEED project to focus on gene environment interactions.

And this will increase the sample size with expected enrollment of over 2,300 children, so doubling the sample size of the SEED project. And as results are available, we will certainly share those with the IACC.

In terms of improving awareness of early signs of autism, Laura Kavanagh mentioned the "Learn the Signs, Act Early." project, which is in collaboration with HRSA and others.

We have 15 new Act Early ambassadors. And these are individuals that are funded in 14 states to work on communication, education, and training related to early identification of autism and other developmental disabilities.

So the new ambassadors have gone through training and are working together to improve early identification.

We also have participating with the meeting that Autism Speaks is sponsoring tomorrow and the day after called Moving the Needle, which is a strategic planning meeting to address barriers to diagnosis and treatment for autism and improving early identification.

So we will certainly, Rebecca Wolf will be participating in that. We have some new materials available on our website. So if you have not gone to the CDC.gov/ActEarly website recently, I would encourage you to go take a look there.

There are free fact sheets, videos, materials, milestones information. And in particular, there is a new interactive book that's available.

We'll be distributing some print copies, but there's also a downloadable PDF version of it. It's called “Amazing Me, It's Busy Being 3!”

And it's a way of parents reading to

their children to engage in interaction. But also it incorporates early developmental milestones throughout the story and it's a more interactive way to teach about developmental milestone.

That book will be distributed to low-income families through the Reach Out and Read program in partnership with the American Academy of Pediatrics and Bright Futures.

So please take a look at the website if you would like any of those materials available.

They're also adaptable, so if you are interested in using them for your state or organization, you can incorporate your own logos and information and modify some of that information so you can use it as well. That's the CDC update.

Dr. Insel: Cathy, are any of those resources available in Spanish?

Dr. Rice: Yes, many of them are. I don't think the Amazing Me book is at this point. But most of the fact sheets and milestones information are available in Spanish.

And there have been some translations to other languages. They may not all be on the web. But if you have a particular interest, you can let me or anyone at CDC know and we'll try to connect you to see if there has been a translation.

Dr. Insel: Thank you.

Ms. Redwood: Cathy?

Dr. Rice: Yes.

Ms. Redwood: Cathy, this is Lyn Redwood. You mentioned with the Somali study that you're also looking at medication use.

There was a report recently from the Minnesota Department of Health that found very high levels of mercury in skin bleaching creams that were being imported illegally into the state.

And I was talking with Idil, who came and spoke before the IACC previously. And she was telling me that those creams are very popular in the Somali community.

So I was wondering if that could be something that you could add to your questionnaire with regard to medication use?

Dr. Rice: Yes, so for the --

Ms. Redwood: Or other kind of use. I can send you the information.

Dr. Rice: That would be great. So the medication use, that was for the SEED study, the Study to Explore Early Development, which is the broader community study. That study is not happening in Minnesota.

Right now, the portion that's been funded through CDC, NIH, Autism Speaks is the prevalence component of the Minnesota Somali project.

So just in terms of the identifying the children. But that other information would be very helpful. We can certainly share it for follow up and future plans that may come up.

Ms. Redwood: Okay, great.

Dr. Daniels: Thank you. Do we have an update from Alison Singer?

Ms. Singer: Yes. The Autism Science Foundation is in the midst of grant review for pre-doctoral fellowships and post-doctoral fellowships.

We received 86 applications this year, which was more than double what we received last year. And interestingly, many were from investigators for whom this would be a first project in autism.

So that really speaks to Question 7 of the IACC Strategic Plan regarding providing funding to expand the research work force and to recruit early career scientists into autism research.

So we were excited about that. And we expect to announce the grant recipients in late March.

We're also still accepting applications for travel grants for members of the autism stakeholder community to attend

IMFAR, the International Meeting for Autism Research which will be in Toronto this year in May.

The travel grant applications are actually due tomorrow. We encouraged all stakeholders to apply. Individuals with autism, parents, siblings, general education teachers, special education teachers, EI providers, students, pediatricians.

We defined stakeholder broadly. And even though the application is due tomorrow, it's really not an arduous application.

We set aside a pool of funds for this every year because it's important that stakeholders are involved in IMFAR, participate at IMFAR, interact with the scientists. And the application is on our homepage.

Dr. Daniels: Thanks, Alison. I accidentally skipped Stephen Shore. Stephen, do you have an update?

Dr. Shore: Yes. I'm continuing to travel around the world consulting and giving presentations on autism.

More and more on self-advocacy, which I find very encouraging as organizations internationally are now becoming aware that people with autism grow up and become adults.

And how are we going to help those individuals advocate in an effective way, you know, that others can understand and then provide support as needed.

Just another thing that I see coming in the future is the impending DSM-5 descriptors. And I'm beginning to see research on the possible effects of the new diagnostic criteria.

And I think the very least that we can say about it is it's going to be quite a period of transition as we now consider autism under a new criteria, at least slightly different criteria.

And the people who now may be considered as having autism who may, in the future, be considered as having some sort of global delay or social communication disorder.

And the question is what are we going to do to help these people as they're moved into other diagnoses? That's pretty much it from this end.

Dr. Dawson: Stephen, this is Geri.

Dr. Shore: Hi, Geri.

Dr. Dawson: And I also wanted to, this is Geri Dawson, wanted to make a comment to the broader committee since you brought up the DSM-5. And Autism Speaks is very concerned about this issue.

Dr. Shore: Oh, I know. And I appreciate that.

Dr. Dawson: Well, and especially because, as you know, there have been a number of studies that have come out over the last several months that suggest that the DSM-5 criteria may not be as sensitive in picking up particularly individuals who are higher functioning, individuals with Asperger's syndrome or potentially females.

But in looking and reviewing those studies carefully, we felt that there were some limitations to that work that's been published. And it made it very difficult to feel confident that, in fact, that the DSM-5 would have low sensitivity.

And so, what we are currently doing is funding four separate research projects to examine the impact of the new DSM-5 criteria. Two of those will be records based, going back to records of ADI and ADOS where we'll reapply the DSM-5.

And that will be done through the AGRE sample. So we'll have thousands of individuals of a very wide age range.

But also, as you know, we helped to co-fund the South Korean prevalence study. So those investigators are going back to a very large sample in South Korea and applying for the first time the DSM-5 criteria to compare DSM-IV and DSM-5.

But a prospective study will be, our

plans hopefully are to build on the study that Cindy Lawler just mentioned, which is that we've funded one of the ADDM sites that is part of the CDC surveillance network to conduct a population based screening study that is similar in methodology to what was used in South Korea, which resulted in a much higher prevalence estimate because it was based on population screening rather than a records based.

And so in that study going forward we are also going to build in the use of both DSM-5 and DSM-IV, which will allow us to compare those and also, I think, could be helpful to the CDC in planning their efforts going forward around surveillance.

And then finally, a fourth study will be conducted through the Autism Treatment Network. Again, looking at consecutive referrals and perhaps over sampling the populations of individuals about whom there is most concerned about the issue of sensitivity.

So I just wanted to let folks know about that since it came up.

Dr. Insel: Yes, that's a great update.

Mr. Ne'eman: This is Ari. I have just a brief, I suppose it's something of a question, something of a suggestion.

You know, we share those concerns regarding the DSM-5, particularly in terms of the need for more data to assess to what degree the sensitivity concerns, you know, are present and at what level.

One issue that, to us, has stood out in the existing data in terms of an absence is the lack of any research applying and comparing the DSM-5 and DSM-IV criteria to how they're applied for various underserved groups.

And in particular, adults, which are often not accurately diagnosed under both the existing criteria and I think there's great concern about the potentials regarding the new criteria, should they not be properly calibrated.

So, you know, I would just encourage whoever's funding research in this area to ensure that there's an inclusion of the adult population as well.

And in so far as possible, to provide some disaggregation to see if any conclusions can be drawn for other historically underrepresented groups such as women and girls, and racial and ethnic minorities.

Dr. Dawson: Those are really great points. And I think the AGRE sample, although it's not perfect, it has, you know, every study has its strengths and weaknesses.

But the AGRE sample in particular, there are adults and really quite a few adults that are part of that sample. And it also, based on an NIH grant, actually has over recruited for certain ethnic minorities.

And so, certainly there are females as well. So we feel that because of the size of that sample, that we may be able to begin to look at those really important questions.

Dr. Insel: Geri, this is Tom. The time frame for what you're doing in terms of the schedule that the American Psychiatric Association --

Dr. Dawson: Right, and you always hate to say, because you know studies, we always are ambitious and then they always take longer than they should.

But if everything lined up perfectly, our goal would be to have the South Korean study done before the fall or by fall because the DSM, my understanding, the new criteria goes to print in December of 2012.

And so we would hope that we would have some information that could inform. And certainly the AGRE study, we're hoping to have that done in time before it goes to print.

The ADDM study and the ATN study will take much longer. And in fact, the ADDM study will be built in to what, really, is going to be a three year project that is a much larger scale project.

But I think we really need to be thinking about the DSM-5 as an ongoing issue. It's not going to be answered with one study.

And as the people who are heading up the DSM-5 committee such as Sue Swedo and others, they've really stressed that it's a working and living document. And we'll hopefully see changes as new data comes in over time.

Dr. Insel: I might just add that from the NIMH perspective, I think many of you know, we've launched this research domain criteria project, which is a different approach to nosology than that taken by the American Psychiatric Association.

And just yesterday and today was the meeting on how we will approach disorders that involve deficits in social processing, social motivation, social communication, social cognition.

So we will be coming out with a

report on the meetings of yesterday and today fairly soon. And this will be part of a much broader effort to provide a different framework for diagnosis.

Dr. Daniels: Okay, do we have an update from Marjorie Solomon?

Dr. Solomon: Yes, you do. To give you a little update on what's been going on at the M.I.N.D. Institute, one of the bigger developments here has been the arrival of a new executive director.

Dr. Leonard Abbeduto, who's a Fragile-X and language and developmental delay researcher who comes to us from the Waisman Center where he worked for about 24 years with Marsha Seltzer in administrative roles in that organization.

So we're really excited to have him. And so now, poor Dr. Abbeduto, he arrived in the middle of the California financial pressures and a tough NIH funding environment.

But we're really trying hard to

adapt and thrive in this new environment. And some of his initiatives and our initiatives are to build more efficient research administration structure to serve both NIH funded research and also to increase our clinical trial presence.

We're beginning to do strategic planning around the application for a major infrastructure grant that looks like, at this point, it will incorporate clinical assessment, more genetics, imaging and immunology under a P30 mechanism.

Our investigators submitted multiple collaborative applications for ACE centers in the last call.

And it's kind of exciting to see how these grants really involve a lot of new collaborations and represent the next wave of research that's resulted from past successful programs of the NIH in studies of environmental epidemiology, immunology, early behavioral and neural development as well as early intervention.

We recently received a large IES grant. Dr. Peter Mundy, our director of educational research, and that's going to really be a major way for us to push more into school based research.

We've also really begun more seriously through our SED and through an Autism Speaks community service grant to talk to our campus about college participation of students with autism, and we have many at UC Davis.

And we're really working hard to develop more succession planning for our faculty. We have a lot of junior faculty that are transitioning to mid-career, as well as some senior investigators that could retire.

And so we're thinking about submitting another training grant to supplement our autism research training program.

And as always, we continue to try to evaluate and better structure our clinical programs to meet the needs of the community and our researchers in terms of their recruitment efforts.

And then, I think pretty much as every organization, we're continuing our development efforts. We are talking about creating a national advisory board as well as a friends program to bolster our national donations.

And we're always looking to increase our partnerships with other similar institutions domestically and internationally, which we see as a real untapped source of potential collaboration. So that's my report.

Dr. Daniels: Thanks, Marjorie. Larry Wexler, do you have a report from the Department of Education for us?

Dr. Wexler: Yes, thank you. Just a couple of things. Many of you are aware that the department's been working on a restraint and seclusion resource document.

That document is ongoing and it remains in clearance. But we're very optimistic of it coming out in, I don't want to say the near future, but we're very optimistic relative to the clearance process.

The point of the document is essentially to support states, school districts, schools and organizations, just giving them some framework in developing their own policies and procedures for restraint and seclusion.

The other, related to the restraint and seclusion, I hope you're aware that on Friday, the Office of Civil Rights will be releasing its first data collection on restraint and seclusion.

That's a national data collection that's part of the Civil Rights data collection. And that's scheduled to be released on Friday. And that's it.

Dr. Daniels: Thank you. Great to know about that. I know many members of our committee were involved in our meetings on seclusion and restraint and will want to take note of that.

Dr. Insel: I think that's it for the entire list. Have we left anybody out who has joined the meeting and wants to give an update?

(No response)

Dr. Insel: Okay. Well, it's impressive. We've got an awful lot happening even though we haven't been meeting.

It's clear that everybody's been busy and I thought it was really timely that we could get together just to hear about the many activities for individual organizations.

I'm impressed by the number of collaborations that are taking place between different members of the committee.

And also, just listening to this over the last hour and a half, how much of what we're doing, it maps well onto the strategic plan. So great to hear about a lot of the new initiatives that are popping up in all these different sectors.

One of the other things we have on

the agenda was I wanted to make sure that there would be time to hear about the update from you, Susan in terms of the Office of Autism Research Coordination.

So let's take a few minutes to get up to speed there.

Dr. Daniels: Okay. I'll start just by reiterating to the committee that anybody who has an upcoming public meeting that you would like to have the public know about through our website, please send it to me or to the office so that we can post that on our website.

And there is an RSS feed that a lot of people are subscribed to and they would get notification of those meetings and how to access them.

In terms of the work that our office is doing, you all have received your first email for this year on the summary advances for 2011, just to finish up that business.

And so nominations are open until

Tuesday of next week, and then we will close that and have you vote. And by mid-March we hope to be writing and producing this document.

And we'll push the document out as soon as possible to the public to let you know what advances took place in the year of 2011. Any questions that anyone has, you can feel free to email me.

On the portfolio analysis for 2010, we are close to being done with collecting data. We have five agencies and organizations that we're still trying to finalize before we have all the data.

We'll be analyzing those data. And simultaneously we're about to begin collecting data for 2011, because our goal is to put out two reports in the same year to get caught up.

And so be expecting a data call for 2011 unless a few people have already submitted their 2011 information to us.

So that work will be ongoing and we hope to have an update at our first meeting of the new committee.

In terms of the next meeting, we won't be able to schedule anything until we're fairly certain of when the committee is going to be fully appointed.

So we will definitely keep everyone up to date about potential dates for that meeting as we learn more about the formation of the new committee.

Alison asked for an update on the letter to the Secretary on seclusion and restraint.

And I have not heard any updates from the department on this and we have not received a response that I am aware of to that letter. But I know that the letter was received in the department last fall.

In terms of the minutes for this meeting, I'll be sending those out to you by email so that they can be approved and put up on the website as soon as possible for everyone.

And I will send you an update about IMFAR (International Meeting for Autism Research). In the past we have sponsored travel. I don't know if we are going to be able to do that this year.

But if we are able to, we will certainly let you know and give you an opportunity to let us know if you would like to be able to attend on behalf of the IACC.

But we will have a booth for the IACC at IMFAR. And, you know, some of us will be able to attend. So I think that is my update, unless anyone has questions.

Dr. Insel: Great, yes. Questions or comments for Susan?

Ms. Singer: This is Alison. There are no activities, IACC activities planned for Autism Awareness month this year?

Dr. Daniels: For right now, we were hoping that we would have a new committee.

Dr. Insel: Yes, the plan was to have our first meeting in conjunction and to invite Congressmen Smith and Doyle along with the Secretary. But at this point, we don't have the appointments completed, so that's on hold.

Dr. Daniels: Unless the current committee has a suggestion of an activity you would like to do and you would like to pursue doing something in the month of April. I'm open to suggestions, and you know, we can have a discussion on that.

Dr. Insel: The other thing we can do is to post activities that are going on in any of your organizations so that we have one place on the IACC's website where those can be noted.

Ms. Blackwell: Tom, this is Ellen. I had suggested to Susan fairly recently that, and I'm not saying that it's appropriate for April, but at some point the committee might want to look at issues associated with older adults who have autism.

Dr. Daniels: So that would be

something that would be of interest to take up. We're a little bit hesitant to start too much new work with the current committee, as we hope that the new committee will be appointed soon.

However, we'll keep you updated and certainly will bring these opportunities to the new committee. But if anyone has a suggestion right now of something that you think we could accomplish before April, let us know.

We are hoping that the Summary of Advances will be released in April.

Ms. Redwood: This is Lyn. I was just wondering from Cathy when you say that the new data will be available in the spring. Is that something that could possibly be made available to the public in April?

Dr. Rice: That's a possibility. It's still going through its final approval process, so we don't have an exact date at this moment.

But certainly, we know there would be quite a benefit to having that available to the autism community before that time. And every effort is being made to make sure that's possible. But I can't say a date at this point.

Dr. Dawson: Ellen, this is Geri. And I just wanted to respond to your comment about information on aging and the elderly and autism.

And just wanted to let you know that Joe Piven's group at UNC received a grant from NIH to begin a program of research in that area.

And so they're actively really working on that, if you wanted to contact him. There's a paper that recently came out that was a summary of a meeting that was held, I think it's been a couple years ago now, but it was on the elderly.

Mainly just describing that there's very, very little known and the need for a full research agenda on that topic.

And then I'm also aware that there's

work being done at the University of Pittsburgh on elderly persons with autism. And so those are just some leads in terms of people you might be interested in talking to.

Dr. Solomon: Another lead in that area is Dr. Hilde Geurts at the University of Amsterdam received the Dutch equivalent of an RO1 last year to do a similar study of the elderly.

And her paper in JADD (Journal of Autism and Developmental Disorders) that shows some of the first neural cognitive testing of that population was presented by Tom at one of our earlier meetings. And that's G, E, U, R, T, S if you want to look for it.

Dr. Daniels: Thanks, Marjorie and Geri. I think that Kathy Greenlee, who is the administrator of the Administration on Aging might be a wonderful person to have at a future meeting of the new IACC to talk about, because there is such interest and people are starting to gear up to look at these very important services and other issues associated with this group.

Dr. Insel: Other comments or questions?

(No response)

Dr. Insel: Okay, well hearing none, I want to thank all of you for joining us for this conference call. It's been extremely helpful to get these updates and to realize how much is going on in all these different sectors.

We will, as Susan mentioned, keep you posted on progress on the IACC front. And you'll be getting additional emails from us about the information that we need to complete some of the documents that are in progress now.

So stay tuned to those. And we hope that you'll be able to respond quickly so we can get some of these things out as fast as possible.

Thanks again. I think, unless there's anything else that anybody needs to bring up, the meeting is officially adjourned. Thanks, everybody.

(Whereupon, at 3:35 p.m., the Committee adjourned.)