

INTERAGENCY AUTISM COORDINATING COMMITTEE
HOUSING NEEDS WORKING GROUP
PLANNING CALL
THURSDAY, JUNE 20, 2019

The Interagency Autism Coordinating Committee (IACC) Housing Needs Working Group convened a planning call at 3:30 p.m. Susan Daniels, Ph.D., presiding.

PRESENT:

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

ALISON TEPPER SINGER, M.B.A., *Chair*, IACC
Housing Working Group, AUTISM SCIENCE
FOUNDATION

SAM CRANE, J.D., AUTISTIC SELF ADVOCACY
NETWORK

DANIEL DAVIS, ADMINISTRATION FOR COMMUNITY
LIVING (ACL)

JILL ESCHER, AUTISM SOCIETY

MELISSA HARRIS, CENTERS FOR MEDICARE AND
MEDICAID SERVICES (CMS)

VERONICA HELMS, U.S. DEPARTMENT OF HOUSING
AND URBAN DEVELOPMENT (HUD)

LORI IRELAND, IRELAND FAMILY FOUNDATION

DESIREE KAMEKA, M.T.S., MADISON HOUSE AUTISM
FOUNDATION

PRESENT: (continued)

ARUN KARPUR, M.D., AUTISM SPEAKS

BEN KAUFMAN, M.S.W., ASSOCIATION OF
UNIVERSITY CENTERS ON DISABILITIES

AMY LUTZ, EASI FOUNDATION

KIM MUSHENO, AUTISM SOCIETY

JOYCE NICHOLAS, SOCIAL SECURITY
ADMINISTRATION (SSA)

KEVIN PELPHREY, Ph.D. UNIVERSITY OF VIRGINIA

DENISE RESNIK, DRA COLLECTIVE

EMILY ROSENOFF, OFFICE OF THE ASSISTANT
SECRETARY FOR PLANNING AND EVALUATION (ASPE)

JAY SHUKERT, PARENT, ADVOCATE

DEBRA TIDWELL-PETERS, SSA

STEPHEN WHITLOW, J.D., MERAKEY TRANSITION
CENTER

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PROCEEDINGS

DR. SUSAN DANIELS: Good afternoon. This is Dr. Susan Daniels, the Director of the Office of Autism Research Coordination at the National Institute of Mental Health. I'd like to welcome everyone to the call. If you're listening in, you might want to stay on mute when you're not talking just to cut down on noise.

We're having this very first call of the IACC housing working group. And we would like to just welcome working group members, IACC members and members of the public who may be listening into this call. We're going to be kicking off the work of the working group.

And I would like to start by doing a roll call to see who's on the phone. So members of the working group, please let me know that you're on as I call your name. So first our chair, Alison Singer.

MS. ALISON SINGER: I'm here. Hi,
everyone.

DR. DANIELS: Hi. Denise Resnik? Stephen
Whitlow?

MR. STEPHEN WHITLOW: Yes, I'm here.
Thank you.

DR. DANIELS: Hi. Desiree Kameka?

MS. DESIREE KAMEKA: Yes, I'm here. Thank
you.

DR. DANIELS: Thanks. Jay Shukert? Lori
Ireland.

MS. LORI IRELAND: I'm here.

DR. DANIELS: Thanks. Ben Kaufman?

MR. BEN KAUFMAN: Hi, Susan. I'm here.

DR. DANIELS: Hi. Scott Robertson? Debra
Tidwell-Peters? Emily Rosenoff?

MS. EMILY ROSENOFF: Good afternoon.

DR. DANIELS: Hello. Kim Musheno?

MS. KIM MUSHENO: I'm here.

DR. DANIELS: Thank you. Daniel Davis?

MR. DANIEL DAVIS: I'm here.

DR. DANIELS: Thanks. Amy Lutz? Jill
Escher?

MS. JILL ESCHER: I'm here. Hi.

DR. DANIELS: Hello. Jill, was Amy there
too? Jill, was Amy there, too? No. Veronica
Helms? And Arun Karpur?

DR. ARUN KARPUR: I'm here.

DR. DANIELS: Thank you. And IACC members
who are members of the working group, Melissa
Harris?

MS. MELISSA HARRIS: I'm here.

DR. DANIELS: Thank you. Kevin Pelphrey?

DR. KEVIN PELPHREY: I'm here.

DR. DANIELS: Thanks. Sam Crane? Jim
Ball? Is there anyone who's a member of the
working group or the IACC that I didn't call?

MS. DEBRA TIDWELL-PETERS: This is Debra
Tidwell-Peters.

DR. DANIELS: Oh, sorry, okay. I heard Debra Tidwell-Peters. Okay. Next, someone else?

MS. VERONICA HELMS: Veronica Helms, U.S. Department of Housing and Urban Development.

DR. DANIELS: Okay, thanks.

MS. HELMS: Thanks.

DR. DANIELS: Anyone else?

MR. JAY SHUKERT: Yes. This is Jay Shukert.

DR. DANIELS: Oh, hi. Others? Okay, great. So we have the group together. So as I mentioned, Ms. Alison Singer, who is a member of the IACC is the chair who has volunteered to work with this working group on the activities of the working group. Alison, would you like to say a couple of words of welcome?

MS. SINGER: Yes. Thank you so much, Susan and everyone at the IACC and the Office of Autism Research Coordination for helping us organize this group.

As all of you know, the issue of housing is critically important. We have a true dearth of appropriate housing options for people with autism. And so our overarching goal for this group will be to explore some best practices for housing for people with autism at all functional levels and to talk about what options might be appropriate and how we can maximize access.

So, again, I want to thank all of the members of the IACC who have joined this group as well as all of the working group members. Thank you in advance for all of the work that you're going to be doing.

Susan, you're going to talk about the timelines or do you want me to talk about the timelines?

DR. DANIELS: So first I'm going to - I'll lay out what else we're going to do on the call. So we're going to go through and let everyone introduce themselves and then we are going to talk a little bit about the mission statement of the group and some of the activities we have coming up, including the workshop that's going to be held on July 23.

But I'd like to give a chance to working group members to just introduce themselves so people can be familiar with who is on the group. And for anybody from the public who is listening in, we do have a Web page created for this group now on the IACC Web site.

You're welcome to visit it where we list the roster, any activities related to the

working group. And we'll continue updating that as things move along.

So first I'd like to just give everyone a chance to introduce themselves. So we can start with you, Alison.

MS. SINGER: Okay. I'm Alison Singer. I am a public member of the IACC. I am the founder and President of the Autism Science Foundation. I am the mother of a 22-year-old daughter who has very severe autism and who lives at the Center for Discovery in Monticello, which is a farming community where she is really happy and thriving.

And I'm also legal guardian to my adult brother with autism. He's my older brother. And he lives in a community-based setting in Suffern, New York.

DR. DANIELS: Thank you. And I didn't fully introduce myself. So I'm Susan Daniels. I manage the Office of Autism Research

Coordination. I've been doing this now for about 10 years and working with the inter-agency autism coordinating committee.

And we have a whole team at the OARC that is involved in helping produce all the meetings and documents and materials that the IACC is involved with.

And so it's a great pleasure to be here. And my background is I'm a neuroscientist but I've been doing autism and science policy for many years now.

So we'll go to the working group members and allow you to introduce yourselves. So I'm just going to go in the order that's listed on the Web site. So Jim Ball I don't think is on the phone. Sam Crane is not there. Daniel Davis.

MR. DAVIS: Hi. I'm Daniel Davis. I'm a health policy analyst with the Center for Policy and Evaluation Office for Policy

Analysis and Development at Administration for Community Living.

And housing is one of my areas of specialization. I've been actively involved in a number of activities around partnering with HUD on various housing projects as well on joint development of certain notices of funding availability.

DR. DANIELS: Thank you. Melissa Harris.

MS. HARRIS: Hi. This is Melissa Harris. And I am with the Centers for Medicare and Medicaid Services in Baltimore, Maryland. I'm in the car at the moment so I apologize if this is not coming through very clearly.

And I am a member of the IACC and I work in the area within the Medicaid program at CMS that handles all of the benefits for the Medicaid program, including the long-term services and support.

And most relevant for this conversation the regulation that defines the criteria of a home and community-based setting for purposes of Medicaid receipt of home and community-based services is one of the provisions that I oversee in my group.

And so I will be providing some technical assistance on how to make sure that the criteria of a home and community-based setting are kept in mind but also to make sure that we're all recognizing the applicability of that home and community-based setting criteria and the various settings that can really be in compliance with it and meet the varying and disparate needs of people who receive long-term services and support in Medicaid, including individuals with autism.

So this conversation will be quite relevant to what I do on a daily basis. And

I'm looking forward to helping the conversation, you know, get off the ground. So thank you for having me.

DR. DANIELS: Thank you, Melissa.

Veronica Helms? You might be on mute from HUD. Maybe we'll come back to Veronica. She might be having phone issues. Kevin Pelphrey?

DR. PELPHREY: Hi. I'm Kevin Pelphrey. I'm a Harrison Woods Professor of Neurology at UVA, University of Virginia. And, let's see, I'm a neuroscience and most relevant for my work as a member of the IACC is that I am father to a son and a daughter with autism and the other kids as well. And looking forward to working with the group.

DR. DANIELS: Thank you. Scott Robertson? Emily Rosenoff.

MS. ROSENOFF: Hi. This is Emily Rosenoff. I'm at the HHS, Office of the Assistant Secretary for Planning and Evaluation or

ASPE. I'm currently the Acting Division Director for Long-Term Service and Support Policy.

And more importantly for this group, I've done a lot of work with HUD thinking about housing models for people with disabilities where we bring together housing and services. So glad to be here.

DR. DANIELS: Thank you. Debra Tidwell-Peters?

MS. JOYCE NICHOLAS: Yes. This is Joyce Nicholas from SSA. I'm filling in for Debra today.

DR. DANIELS: Okay, great.

MS. NICHOLAS: But I will speak for both of us in that we work within the Office of Research, Evaluation and Policy here at SSA. And our office does do a great deal of homeless related work, whether the quantitative analysis or considering the

needs of homeless individuals while conducting various demonstrations and pilots.

DR. DANIELS: Thank you. Jill Escher.

MS. ESCHER: Hello. I am a landlord based in the Bay Area of California. I am currently renting 12 community-based generic apartment units and housing units to adults with developmental disabilities, almost all of whom have autism from very severe to rather quasi-independent.

I'm also the mother of two children with non-verbal forms of autism who live at home with me. And I'm President of Autism Society, San Francisco Bay Area, and President of the National Council on Severe Autism.

DR. DANIELS: Thank you. Lori Ireland?

MS. IRELAND: Sorry. I was on mute. This is Lori Ireland. I'm the Vice Chair of the Autism Society of America. I have an adult son on the spectrum who is moderately,

severely impacted depending on how we measure those things.

I have worked in various roles across the autism spectrum and I'm looking forward to working with everyone.

DR. DANIELS: Thank you. Ben Kaufman?

MR. KAUFMAN: Hi, everyone. I'm Ben Kaufman. I work at the Association of University Centers on Disabilities. A lot of our members have expertise in housing, including developing and implementing housing initiatives with and for people with development disabilities.

My role is specifically providing technical assistance to the network of CARES-funded LEND program, the LEND training programs and developmental pediatrics training programs.

I'm a social worker by training. And relevant to this group, I have a younger

brother who is autistic and has some rather significant support needs who very recently was approved for residential services through our state's waiver system and so have recently navigated the housing process with him and other members of my family. So looking forward to working with everybody.

DR. DANIELS: Thank you. Kim Musheno.

MS. MUSHENO: Hi. Thank you. My name is Kim Musheno, Vice President of Public Policy for the Autism Society of America. And I've worked in various national organizations for practically 25 years in the digital policy arena. And am the immediate past chair for the Consortium for Citizens with Disabilities.

I have a brother-in-law with autism and also helped him navigate the residential services world. And I belong to the housing task force of CCD.

DR. DANIELS: Thank you. Desiree Kameka.

MS. KAMEKA: Hi. My name is Desiree Kameka. I'm the Director of Community Engagement and Housing Networks for the Madison House Autism Foundation. I lead three housing initiatives on online platforms. It's called the Autism Housing Network, which provides a hub of housing information.

I lead the empowering communities initiative, which is where I offer presentations and consultations, presentations to help local communities under the benefits and considerations of different property types and service delivery models as well as consult with emerging projects, local solutions who want to develop housing in their communities.

And then I also am the National Coordinator for the Coalition for Community Choice, which acts to make sure that policy

is increasing options and decreasing barriers to the housing and support choices of people with autism and other developmental disabilities.

DR. DANIELS: Thank you. Arun Karpur?

DR. KARPUR: Hello there. I am the Director for Data Science and Evaluation Research at Autism Speaks. I come from the background in disability studies. Before joining Autism Speaks, I was at Cornell's School of Industrial Labor Relations for the faculty.

I have specifically, recently led the New York State PROMISE initiative, which was a program to improve transition to adulthood for youth and young adults with disabilities.

My background is in clinical medicine and epidemiology and biostatistics. I am a quantitative data scientist that is proficient in utilizing public and

administrative data bases for program evaluation and public policy research.

DR. DANIELS: Thank you. Amy Lutz?

MS. AMY LUTZ: Hi. Thank you. I am the President and founder of EASI Foundation, Ending Aggression and Self-Injury in the developmentally disabled. And I am on the board of the National Council of Severe Autism. And I have five children. My oldest is 20 years old. And Jonah has severe autism.

DR. DANIELS: Thank you. Denise Resnik.

MS. RESNIK: Hi. I am the founder, President and CEO of First Place, which has been open just under a year. It's 55 unit, 81,000 square foot apartment community in the heart of our urban area that has a mix of uses, including a transition academy for students, apartment, supportive housing for diverse abilities and a global leadership institute.

It's the result of more than two decades of exploration of over 100 properties across the country in collaboration with Urban Land Institute and Arizona State University and others and a whole lot of work and also the result of 22 years of community building as co-founder of the Southwest Autism Research and Resource Center.

I'm the mother of a 28-year-old son with autism and have been involved in the real estate industry for more than 35 years as a marketing communications consultant.

And we finally pulled the trigger on doing the real estate ourselves and what we hope will be introducing a new wave of residential and community options for people with autism and other neurodiversities, planning and envisioning that they will be as bountiful as they are for everyone else.

DR. DANIELS: Thank you. Jay Shukert?

MR. SHUKERT: Yes. This is Jay Shukert. I'm the father of a 34-year-old son of relatively high functioning autism. He lived in the Adaptive Learning Center in Concord, California, for a number of years and now is living independently with some assistance from us in an apartment. We're in San Francisco.

And I work as a Chief Financial Office for a biotechnical and medical technology company.

DR. DANIELS: Thank you. Stephen Whitlow.

MR. WHITLOW: Yes, good afternoon. My name is Steve Whitlow. I have a son who is 19 and is on the spectrum. And I'm a lawyer by trade. About five years ago my wife and I started a nonprofit that is a transition center with a T-shirt company attached to it that we use for motivational training.

And as a part of that we ended up linking up with a nonprofit called Merakey when we were provided with the opportunity to provide some housing options.

And so I have since gone to work as the Transition Director for Merakey. And our goal at Merakey is to try to find ways to weave in the actual programming with housing. And I'm working on a couple of projects to do that. And Merakey runs the Heidelberg property, which is a (unintelligible) for autism and neuro-diverse autism housing project in Pennsylvania right now. So I'm excited for this group to get together. I'm thankful for everybody for donating their time. And I look forward to working with everybody.

DR. DANIELS: Thank you. Is there anyone that didn't have a chance to introduce themselves?

MS. SAM CRANE: Hello. This is Sam, I just joined.

DR. DANIELS: I'm sorry. I couldn't hear you very well.

MS. CRANE: I think two people spoke at once. This is Sam. I just joined the call.

DR. DANIELS: Oh, hi. Sam, would you like to introduce yourself?

MS. CRANE: Yes. This is Sam Crane. I am the legal and public policy director at the Autistic Self-Advocacy Network. We are the nation's leading self-advocacy organization led both by and for autistic people ourselves.

And as Director of Public Policy, I oversaw a summit recently in which we brought together self-advocates of diverse backgrounds and support needs to talk about the meaning of community living and the importance of happenings in community living.

And we just issued a report discussing our findings at our Policy Center office. So we're very interested in this issue.

DR. DANIELS: Thank you. And was there somebody else who also was trying to speak? Okay. So I'm not hearing anyone. If there is someone who joined, you can let us know as we continue through the call.

So I'd like to turn to the mission statement of the group, which is something that Alison Singer developed and shared with the IACC at one of their recent meetings.

And the IACC did not have any edits to make to it, but we wanted to present it to the group. And if there are any tweaks that need to be made to it, you can let us know either on the call or offline.

But the mission statement, I don't know if Alison has it front of her, I have it in

front of me. So I can probably go ahead and read it unless Alison wants to.

So in the autism community we face a mounting housing crisis with a growing population of autistic adults with diverse needs lacking appropriate living situations.

The goal of this working group is examine a wide variety of housing options and service models for people with autism, focusing on strategies to achieve a broad array of supported housing options throughout all of our communities that enable autistic individuals to achieve person-centered outcomes.

So that is the mission going forward. And as I've shared via email and members of the public have heard some of this in our last IACC meeting as well that this working group is going to try to foster a robust discussion on the issue of housing and the

different kinds of options that are available for people.

And we're going to in large part do this through a workshop that we're holding on July 23, 2019. It will be held at the Hilton Washington in Rockville, Maryland, which is near where the NIMH building is. And it's the same location where we're going to have the IACC meeting the following day.

So we put both meetings together in the same location to facilitate people who might want to attend both. And working group members are welcome to attend the IACC meeting if you wish.

So we will be having this workshop. It's going to be from 9:30 to 4:30 on July 23. And we really thank members of the working group for being so responsive in sending us wonderful nominations of people who could potentially speak at this workshop.

Alison and I were so pleased to see the variety of nominations. And we'll be going through that and trying to put together a diverse program based on your recommendations.

And, again, we're just really impressed with the wide array of suggestions from across the nation in various communities that are trying various models and using various approaches to helping people navigate through the housing process. So we'll keep you up-to-date as that develops.

And with this working group given the timeline of the IACC, so the IACC, as you all know, the Federal Advisory Committee that's authorized by Congress through the Autism Cares Act of 2014, which is the latest authorization, that authorization is going to be completed at the end of September 2019.

And so we are coming in to the tail end of the committee. And this July 24 IACC full committee meeting is our last meeting before the committee will hopefully turn over to the period where they start the work on the nominations of the next group.

So the Secretary of HHS will select new public members for the committee with the reauthorization. And we do hope and anticipate that there will be reauthorization of the Autism Cares Act.

So we have a pretty short timeline to work with. And given that we don't anticipate that we will likely be able to write an original document about housing just because of the timeline, but we hope that this workshop is an opportunity for really sharing a lot of interesting and stimulating models that could be used in various settings across the country to help provide options for

people with varying levels of abilities and disabilities within the autism community with appropriate housing.

And with the working group, we are hoping that everyone will very much participate in that discussion and raise issues, engage with the speakers who are there. And there will be a workshop summary after that and then the following day we'll have Alison share a summary of what happened in the workshop with the committee.

And so this really is the starting point of the committee's work on this issue. And the next iteration of the committee will have an opportunity to continue work on this issue.

But many times discussions within the IACC really raise issues to the forefront for people across the community and for federal

agencies just to hear public input, which is a major role of the committee.

So we anticipate that this workshop will help break some exciting ground in this area and just bring people together to discuss various types of models that might be promising for use across the community.

So those are the activities we're planning. We may or may not have additional phone calls depending on how the workshop goes and what additional steps we might need to take to make sure that the work that is done there is concluded in a way that it can be used in the future.

But we also really look forward to various federal agencies participating in the workshop and hearing from various corners of the community that are trying things.

And we know federal agencies are deeply involved in many of these projects as well.

But all of us, I think, sometimes don't have a chance to hear everything that's going on across the nation. And so we hope that we'll have a nice slice of that to share.

Are there any comments that, Alison, first that you would have to add to what I've said?

MS. SINGER: Yes, I would just - I really appreciate that the full IACC recognized how important it is to focus on this issue before the IACC sunset. And discussion by the IACC on July 24 will be a key step in developing policy and advising the Secretary as it will set up the new IACC when it is reconstituted to move forward with this issue.

We will be providing them with data and information from which they can choose to make specific policy recommendations early in their tenure.

So I think our work is critically important. And, again, I really appreciate everyone taking the time to focus on this and to commit to this intensive schedule.

DR. DANIELS: Yes, agreed. And are there any members of the working group that have comments or questions about what I've just shared or what Alison has shared as well?

So we really look forward to doing this. We didn't really have plans particularly for a policy discussion on this call. It was really more of a planning call to get you all introduced to each other and to the work that we will be doing. And, as I said, a lot of that work will just take place at the meeting itself.

And I know a number of you have said that you are interested in attending the IACC meeting the following day, which is terrific. We welcome your presence there.

And some people that participate on this working group may also be interested in putting in nominations for being on the next iteration of the IACC. So after the committee has been reauthorized by Congress, we would be putting out a call for nominations that is open to members of the public from across the nation and U.S. territories. So please keep that in mind and also people that you know in your circles who might be interested in serving on the IACC.

Are there other comments or questions regarding the workshop and the day that we'll have for the workshop? We do plan to have public comment and the announcements that we've already put out the street we've sent some announcements out. And we have information on our Web site. As the agenda becomes more finalized for the workshop and

the IACC meeting we will be posting those online as well.

And some of the discussions that we will have at the IACC meeting may be of interest to you as well. And so we will be posting information about that online.

Any other questions or comments? I know we set aside an hour and a half just in case there were a lot of comments or questions that had to do with this topic.

I know it's a really robust topic for us to talk about. There are many different angles to it. But since we haven't even had our workshop yet where there will be so much information shared, we maybe don't have quite a starting point yet.

But following the workshop, if we think it's necessary, we can also hold a call to talk more. But I hope that a lot of exciting

discussion will happen at the workshop itself.

So you will be hearing from our logistical contractor about travel for the workshop and everyone is welcome to attend in person but we also will have phone lines and a webcast going. If you watch on the webcast, you will want to call in on the phone line so that you can speak up during the meeting.

And, of course, we're happy to provide reasonable accommodations to anybody who needs them. So let us know if you have a special need for that travel. And we will have a quiet room onsite for both days of those meetings.

And working group members will also have a chance between meetings to meet IACC members if you would like. And I will share more about that via email. Go ahead.

MS. IRELAND: Susan, this is Lori Ireland. And at risk of sounding slightly unprofessional, I am planning to be there in person. But there is a chance that my daughter will go into labor, and if she does go into labor, I will not be there in person. But my associate Kim Musheno will be able to participate on my behalf if I am not able to attend.

DR. DANIELS: Okay. And Kim is on the working group as well. Thanks for letting us know. That is very exciting. And I'm sure that everyone will completely understand if you have to be gone so.

MS. IRELAND: Thank you.

DR. DANIELS: Wonderful.

MR. DAVIS: This is Daniel from ACL. A quick process question regarding in terms of construction of the agenda for the workshop. How is that going to - any sort of - any

basics on the process of how the agenda is going to be constructed or?

DR. DANIELS: So we've accepted nominations from across the working group. And like I said, we have a large number of those that we've received, including nominations that you've made, Daniel.

Alison and I are going to go through that and try to put together an agenda that reflects kind of the diversity of different nominations that came in and group them in a logical way so that we can hear from different parts of the community that are either trying interesting models or that have options about navigating housing systems or data about housing.

So we got quite a nice variety. So the process on our side is going to need to be simple. And so Alison and I will work

together with the nominations that you presented.

But if anyone on the working group has additional nominations that you're just thinking of now that you forgot, please send me an email with the information about that and we'll take it into consideration as we put together what we hope will be a really exciting agenda and a variety of information.

We will have public comment at the workshop and we'll look for - we're actually thinking about some ways that we can incorporate views from people who are being served by some of these different housing options and other people from the community as well.

So we're going to keep all of that in mind. Just try to make this definitely not a dry government meeting of just data but really people's experiences and people being

able to share what are the key elements of their models that are working or that are innovative and how people are being served and people that can respond to that and share their experiences

(Crosstalk)

MS. CRANE: Oh, sorry.

DR. DANIELS: Go ahead.

MS. CRANE: Will we know who is going to be speaking far enough in advance? Because there are probably who, you know, we've nominated. But if they're not going to be invited, we want to make sure that they at least submit a public comment.

DR. DANIELS: Sure.

MS. CRANE: So would we know well enough advance to get them to do that?

DR. DANIELS: I think so. So we're really aiming to get this agenda together within the next two weeks, I would say. I mean, I would

like to say next week, but it might take up to a couple of weeks to get an agenda together.

But as soon as we have one together we'll share it with the working group. And, of course, we will publish it online when it is in a format that's appropriate to put online.

So we will have it online in advance. But we're making - you know, we're in a good position. Like I said, we got some really excellent nominations. So we have a lot to work with.

MS. KAMEKA: Dr. Daniels, this is Desiree with the Madison Health Autism Foundation. I found that many states have different terms for different types of service and delivery or property types.

I've done my best to create a one page workshop to try and define some common

nomenclatures. Obviously this is something that I have put together and it is the language in which I have gathered with descriptions.

I would be happy to share that with the working group work if it could possibly be helpful in terms of being able to use common language to describe different types of property as well as service delivery models.

DR. DANIELS: That sounds great if you can send that to me. What we'll do is we will be preparing a set of resources as a part of preparing for this workshop. And anyone across the working group who has resources, whether it's some sort of a fact sheet, a Web site, a report, any kind of publication, something you think would be helpful to the working group in thinking broadly about the issue of housing for people in the autism spectrum.

You can send those directly to me and we are going to be compiling those into a list of resources for the working group to use and for the public to be able to access. So please share those with me along the way if you think of them.

Also any government agencies that have initiatives or programs that relate to housing that you would like the autism community to be aware of so that they can either apply for those programs or just to make them aware of maybe some of the information or outcomes that you're getting from those programs, feel free to share that information with me. And we will compile it and put it out as a part of your meeting materials for the working group workshop.

MR. DAVIS: And when would you want those submitted by?

DR. DANIELS: You can submit them on a rolling basis. Probably it would be great anything that we really want for the workshop if we have it at least two weeks before the workshop. But if you have them in mind now and you know of a couple of things, feel free to just send them over and I'll just keep collecting them.

I may send out in a future an email to you all a harder deadline about that so that we can make sure our materials are ready in time for the workshop.

MS. ROSENOFF: Hi. Can you clarify the audience for these materials again?

DR. DANIELS: Yes. So the audience will be our working group in terms of we will share it with the working group but it will also be posted online. So, of course, make sure that you're not sharing proprietary or

sensitive information that can't be shared publicly.

So if you have, say, a Web link to a report that's been published or a link to a publication, we can put that up. If you have links to initiatives or press releases or any other kinds of items that you think will share useful information but anyone in the public would be able to access these as well.

And so once we receive them here in the OARC, we'll try to go ahead and organize them into some logical groupings. And also, yes, we don't want people's personal photos and things like that. We want just, you know, documents and reports and resources for people.

MS. ROSENOFF: Great. Thanks.

DR. DANIELS: Anything else that comes to mind? Well, great. Well, I'm not hearing

anything else. Alison, do you have any other final comments?

MS. SINGER: No. Just a thank you for all the work you've already done and all the work that you'll be doing in the next couple of weeks with me.

DR. DANIELS: Yes. And, oh, with the resources as well, any policy documents that you may have that you think are useful. I know CMS has a number. If you can send those over to me, we'll put them in the resources section.

But, yes, thank you so much for your excellent response to the request for nominations and just for agreeing to be a part of this working group to look at this incredibly important issue. It's one that in the OARC we hear about all the time from members of the public.

As you know, many people are very concerned and have a lot of needs in this area. So they will be very appreciative of the work that you're going to doing on this. And many of you, of course, dedicate your careers and parts of your advocacy work to this issue.

So thank you so much and we'll be in touch by email and look forward to hosting you at the workshop in a few weeks. Thank you. Have a great afternoon.

(Whereupon, at 4:10 p.m., the Committee adjourned)